

THE LIVED EXPERIENCE OF A BONE MARROW TRANSPLANT SURVIVOR

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ABSTRACT

Bone Marrow Transplantation (BMT) has progressed from an experimental therapy to a viable treatment for cancer. While the prospects for long-term survival following the procedure has increased, little is known about the quality of this survival. The present study was intended to explore the thoughts, perceptions and feelings of one BMT survivor regarding his/her lived experience with the BMT procedure.

The following questions were developed for the study: (1) What thoughts, perceptions and feelings does a BMT survivor have regarding the lived experience of the BMT procedure? (2) How does a BMT survivor perceive the BMT procedure has affected his/her quality of life? (3) What interventions and support measures would a BMT survivor recommend to health care professionals to enhance the care received? A qualitative case study design was employed to investigate the lived experience of one BMT survivor. This case study was an in-depth investigation of a single individual over time.

The BMT survivor for this study was a 37 year old, white, married male. His original diagnosis was in 1990 of duodenum cancer. Then in 1991 he was diagnosed with T-cell lymphoma and underwent BMT in the summer of 1992. The data collection instrument utilized in this study assisted in obtaining descriptive information from five, one-hour, face-to-face focused taped interviews. Through taped interviews, the researcher and subject explored aspects of the BMT experience that were important to the subject and the researcher attempted to discover patterns and conceptual themes to understand the BMT situation as lived or experienced by the subject.

The conceptual themes that were evaluated from this study were spiritual, psychological, physiological and social. The themes emphasized thoughts and feelings about hope, positive attitude, a philosophy for living, control, stress, fear, returning to normal, desire for knowledge, side effects, nutrition, body image, roles and relationships, isolation, social connection and intimacy. Based on the findings of this study major implications for advanced nursing practice include providing relevant client information, establishment of a relationship with health care professionals that promotes a caring and sincere interest, participation in decision making and the implementation of knowledgeable interventions for managing physical changes.

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CHAPTER ONE

THE PROBLEM

Overview of the Problem

Over the past decade, bone marrow transplantation (BMT) has become an alternative to conventional cancer treatments. BMT represents a major medical advance. To most who have this procedure, it offers the only hope for long-term survival. The ability to prolong survival, however, is only part of the value of any treatment. The lived experience of survival from the patient's perspective is of equal importance. Understanding the lived experiences of persons who have undergone the BMT procedure can assist nurses in counseling patients who are considering BMT as a treatment option. Attention to qualitative aspects of BMT also can lead to changes in current nursing protocols in all phases of the transplant process.

BMT has progressed from an experimental therapy to a viable treatment. The procedure, however, is complex, lengthy and demanding. It is associated with many potential life threatening complications both during and after transplantation (Belec, 1992).

Transplanted marrow can either come from patients themselves (autologous transplantation) or from a

relative with an identical set of immunologic markers usually a sibling. Patients who undergo BMT receive high doses of chemotherapy and/or radiation to eliminate any cancer cells remaining after previous treatment and to produce sufficient immunosuppression to prevent rejection of transplanted bone marrow (Baker, Curbow and Wingard, 1991). After this intense course of treatment, patients then are infused with the marrow and started on a course of therapy to prevent infections. Because their immune systems are not functioning, patients are at risk for severe infections. Consequently, they spend approximately 40 days as inpatients. After this time, patients have to usually discontinue school or work for an additional 6-12 months to recover from the procedure. Although the treatment offers a possibility of cure, it clearly creates many personal burdens.

The number of BMT procedures reached 25,000 by the end of 1988 and continues to increase (Ferrell, Schmidt, Rhiner, Whitehead, Fonbuena and Forman, 1992). As the number of individuals surviving cancer through treatment has increased over the last decade, there has been growing recognition of the importance of conducting research on the lived experience of the survivors. This appears to be part of an increased trend to include quality of life outcomes in the evaluation of the

effectiveness of some medical treatments (Rhiner, Clark and Fogelberg, 1992). The population of BMT survivors represents a group of people for whom the concept of a lived experience takes on special meaning. At a basic level, an issue of concern is whether the ordeal of a demanding therapeutic modality is worth it, given the experience that a person may expect during and after the treatment.

Much of cancer research has focused on response rates, disease-free survival and absolute survival. Research on the lived experiences of persons who have had a BMT is a logical next step in the evolution of clinical nursing oncology studies (Ochs, Mulhein & Kum, 1988). In 1991, Altmaier, Gingrich and Fyfe studied BMT survivors in four areas. These areas included physical health, personal functioning, mental health and role functioning. They revealed study in one area of this experience did not predict function in another, suggesting possible dissymmetry in the subject's feelings about the BMT experience.

Nurses who care for BMT survivors also have revealed different conclusions expressed by patients about the qualitative aspects of BMT. More than one patient has indicated that he/she would not make the same choice again to undergo BMT. The challenge for

nurses, therefore, is to have an increased understanding of what BMT survivors have experienced from their perspective and to use this knowledge to provide more holistic nursing care in order to facilitate patients to resume as a normal, productive life as possible. There has been limited research about the extent of thoughts, perceptions and feelings associated with BMT. Without this information, it is impossible to develop effective nursing interventions and support services for these individuals. Because nurses are often the group providing care and support for BMT persons, an understanding of the lived experience is essential for the advancement of nursing knowledge.

Purpose of the Study

The purpose of this study was to explore the perceptions of a BMT survivor regarding his/her lived experience in order to examine the qualitative aspects of the BMT experience. Specifically, the purpose of this study was to analyze the thoughts, perceptions and feelings of one BMT survivor regarding his/her lived experience of the BMT procedure.

Research Questions

The following research questions were developed for the study:

1. What thoughts, perceptions and feelings does

a BMT survivor have regarding the lived experience of the BMT procedure?

2. How does one BMT survivor perceive the BMT procedure has affected his/her quality of life?

3. What interventions and support measures would a BMT survivor recommend to health care professionals to enhance the care received?

Definition of Terms

Key terms in this study were bone marrow transplant (BMT), lived experience and survivor. Bone marrow transplantation (BMT) was defined as the transference of human marrow which includes the stem cells that can divide and produce all blood and immune cells from one person to another. Transplantation of marrow from twin (syngeneic) or tissue type-compatible (allogeneic) donors have been used to restore hematologic and immunologic capacity after high intensity chemotherapy and radiation treatment of various malignant diseases. For this study, BMT involved the time before, during and after the procedure.

Lived experience was defined as the personal involvement, thoughts, perceptions and feelings of living through the BMT event. Survivor was defined as any person who had received a BMT for potential cure of

a diagnosed cancer and was post transplant for six months.

Overview of Conceptual Framework

The central focus of Watson's conceptual nursing model is human care. Human care, as conceived by Watson (1988), is an intersubjective process and an epistemic endeavor that includes human-to-human transactions. Watson (1988, pp. 27-30) proposed that human care begins when the nurse enters the phenomenal field of the client and is able to detect, feel and respond to the client's condition in such a manner that the client releases subjective feelings or thoughts that the client has longed to release.

Within Watson's model, nursing is conceptualized as a human science of health-illness-healing experiences that are mediated by professional, personal, scientific, aesthetic, and ethical human care transactions. Watson viewed these human care transactions as foundational to professional nursing care as they connect the one-caring-for with the one-cared-for.

Watson proposed that the ideal caring relationship, the transpersonal caring relationship, is a transformative force. Transpersonal caring occurs when one enters the subjective lived experience of another and allows the other to enter his or her experience.

The nurse affects and is affected by the person, with each becoming a part of the other's life history and coparticipants in the now and the future. It is a spiritual union that transcends self, time, space and the life history of each other (Watson, 1988). This shared union frees both from their separation and isolation and potentiates self-healing, discovery, and finding the meaning of existence.

Similar to this study, Watson's model places a high value on the subjective-internal world of the experiencing person and how the person is perceiving and experiencing health-illness conditions. The model also emphasizes helping a person to gain more self-knowledge, self-control and readiness for self-healing, regardless of the external health condition.

Initial Review of the Literature

There is a paucity of literature related to the experience of survivors with cancer and few systematic empirical studies have been completed (Andrykowski, Henslee & Farrall, 1990). There is evidence, however, that survivors experience significant psychosocial, spiritual and physiological changes from the BMT procedure. The study by Andrykowski et al. (1989) suggested emotional readjustment posed a greater challenge for BMT survivors. Yet the results also

indicated physical and psychosocial functioning varied considerably among the BMT survivors. Altmaier, Gingrich and Fyle (1991) compared BMT survivors to a matched sample of patients receiving maintenance chemotherapy and concluded BMT survivors appeared to demonstrate a lower quality of life than the matched sample. The qualitative study conducted by Ferrell, Schmidt, Rhiner, Whitehead, Fonbuena and Forman (1992) explored the concept of quality of life for BMT survivors and concluded that the survivors believed BMT gave them a second chance at life but felt a negative consequence concerning side effects and constant potential for recurrent illness. Wolcott, Wellisch, Fawzy and Landsverk (1986) surveyed the adaptation of BMT survivors regarding health status, mood, social role, self esteem and life satisfaction. The study found that 25% of the BMT recipients reported ongoing medical problems, significant emotional distress, low self-esteem and less than optimal life satisfaction.

Significance to Nursing

Data from this study offer nursing new insights into understanding the BMT as a lived experience. With this information, nurses can alleviate misconceptions related to the procedure and decrease the unknown fears pre and post BMT. In addition, nursing can promote

interventions aimed at enhancing life during and after BMT procedure.

Nurses are concerned about patient issues and worries. It is not surprising that patients with cancer suffer from many physical, psychological, social and spiritual concerns. Cancer is a disease that tries not only physical resistance but spiritual equilibrium as well. BMT and its consequences can create severe emotional strains. Patients feel anxiety, uncertainty, depression, and in particular defenselessness. A basic problem for patients can be the need to resume as normal a life as possible, but at the same time always to be cautious of symptoms and to stick to rules. Preparing patients for this procedure is essential to the outcome of the patient's life. Nursing needs to discover what a patient feels before, during and after this transplantation in order to help individuals find meaning and self control with health-illness decisions.

With further research and understanding of a patient's hopes, fears and feelings of BMT as a lived experience, nurses can provide holistic care by planning and providing more realistic goal expectations for the patient. The patient needs to know that nurses are just as concerned with what goes on in their hearts

and head, as what goes on in their livers and bone marrows. In addition, human care theory and knowledge can be viewed as a significant pursuit in expanding nursing's body of knowledge and nursing as a human science.

Summary

Bone marrow transplantation is a procedure that is complex, lengthy, demanding and encompasses many potential life threatening complications. Limited knowledge is available to nurses as to what clients experience during the BMT procedure. The purpose of this study, therefore, was to explore the perceptions of a BMT survivor regarding his/her lived experience. It was hoped that the study would offer new insight into understanding what BMT clients experience in order to provide nursing with a broader body of knowledge regarding oncological clients in general and BMT clients specifically.

CHAPTER TWO

REVIEW OF THE LITERATURE

The purpose of this study was to explore the perceptions of a BMT survivor regarding his/her lived experience in order to examine the qualitative aspects of the BMT experience. This chapter is divided into three sections. The conceptual foundation for the study is described in the first section. Section two presents a review of research relevant to the study. A summary concludes the chapter.

Conceptual Framework

Advancement of technical medicine today has challenged nursing and the art of caring to coexist. In today's world, nursing seems to be responding to the machinery, with less consideration of the needs of the person attached to the machine. When discussing or caring for a client with a BMT, nursing must achieve a delicate balance between scientific knowledge and humanistic practice behaviors.

The Human Science and Human Care model proposed by Watson (1988) provided the theoretical basis for this study. The central focus of Watson's model is human care. This caring is an intersubjective process that

includes human-to-human transactions. The model is concerned with preserving human dignity and restoring and preserving humanity in the fragmented, technological, medical cure-dominated health care system (Parker, 1990). Watson's framework requires an expanded view of nursing, science, person, environment and health-illness. Her proposed human caring process demonstrates respect for the individual humanness of both the patient and the nurse in a caring relationship. Therefore, the caring model proposed by Watson is an excellent match for helping individuals who have a cancer diagnosis.

Watson (1988) has adopted from nursing heritage some basic and common themes. They are:

1. A view of the human as a valued person in and of him or herself to be cared for, respected, nurtured, understood and assisted to become a fully functional self.

2. An emphasis on the human relationship and transaction between persons and their environment and how this interaction affects health and healing.

3. An emphasis on the human-to-human care transaction between the nurse and person and how this transaction affects health and healing.

4. An emphasis on the non-medical processes of

human care and the nurse's caring for persons with various health-illness experiences.

5. A concern for health and the promotion of health and well-being.

6. A position that nursing human care knowledge is distinct from, but complementary to, medical knowledge (p. 14).

Watson viewed nursing as a human science, combining and integrating the science of nursing with the beauty, art, ethics, and esthetics of the human-to-human care process in nursing (Marriner-Tomey, 1989). As a human rather than a traditional science, nursing can view human life as a gift to be cherished. Watson contended that this approach to nursing can expand nurses' thinking and allow nursing to develop new pictures of what it means to be human, to be a nurse, to be ill, to be healed, and to give and receive human care (Watson, 1988, p. 17).

According to Watson (1988), nursing is defined as a human science of person and human health. "It is illness that is mediated by professional, personal, scientific, esthetic, and ethical human care transaction" (p. 54). Caring is viewed as the moral ideal of nursing. It consists of transpersonal human-to-human attempts to protect, enhance

and preserve humanity by helping a person to find meaning in illness and gain self-knowledge, control and healing to restore harmony (p. 54).

Watson proposed that nursing must foster the person as an end and not a means in a highly technological society and promote caring when humanity is threatened. Caregivers need to understand lived experiences of patients in order to provide holistic care that addresses the physical, mental, spiritual and psychological dimensions of persons.

Watson defined health as "unity and harmony within the mind, body and soul. Health is also associated with the degree of congruence between the self as perceived and the self as experienced" (p. 48).

According to Watson, caring represents all the factors that the nurse uses to deliver health care to the client and proposed ten carative factors that nurses must include in the transpersonal caring process. The following ten carative factors comprise Watson's health-value system:

1. Humanistic-altruistic system of values
2. Faith-hope
3. Sensitivity to self and others
4. A helping-trusting human care relationship
5. Expressing positive and negative feelings

6. Creative problem-solving caring process
7. Transpersonal teaching-learning
8. Supportive, protective, and/or corrective mental, physical, societal, and spiritual environment
9. Human needs assistance
10. Existential-phenomenological-spiritual forces (Watson, 1988, p. 75).

To Watson, human caring is not just an emotion, concern, attitude, or a desire. Caring is the moral ideal of nursing whereby the end is protection, enhancement, and preservation of human dignity (Watson, 1988). As disease issues tend to be shifting from infectious bacteria-linked etiologies to tension-linked etiologies, nursing care is becoming more aware of stress-related health problems and the need to be more knowledgeable about non-medical skills of human caring.

In order for nursing to be responsive to the needs of society, the health care delivery system must be based on human values and concern for the welfare of others. Watson's value system consists of deep respect for the wonders and mysteries of life, acknowledgment of a spiritual dimension to life and the internal power of the human care process such as growth and change. There is a high regard for human autonomy, freedom of

choice and an exploration of how a person is perceiving and experiencing health-illness conditions (Watson, 1988). The nurse is viewed as a coparticipant in the human care process. A high value, therefore, is placed on the relationship between the nurse and the person. It is this transpersonal caring relationship that enables the nurse to detect the subjective world or experience of the client.

The major assumptions of Watson's model are:

(1) Caring can be effectively demonstrated and practiced only interpersonally; (2) Caring consists of carative factors that result in the satisfaction of certain human needs; (3) Effective caring promotes health and individual or family growth; (4) Caring responses accept a person not only as he or she is now, but for what he or she may become; (5) A caring environment offers the development of potential while allowing the person to choose the best action for himself or herself at a given point in time; (6) Caring is more healthogenic than it is curing. It is complementary to the science of caring; and (7) the practice of caring is central to nursing (Marriner-Tomey, 1989, p. 168).

Watson has directly drawn upon the sciences and humanities in developing her model, which has a

phenomenological-existential and spiritual orientation. Watson also attributes her emphasis on self upon the ideas of Carl Rogers, but she has been directed by her own values and beliefs about "the person" and life which reflect her concept of person and her ideas concept with most certainly eastern philosophy. Sally Gadow's works on existential advocacy was also a source of inspiration in Watson validating her ideas.

Watson's (1988) transpersonal human care and caring transactions are those scientific, professional, ethical, yet esthetic, creative and personalized giving-receiving behaviors and responses between the nurse and client that allow for contact between the subjective world of experiencing persons (p. 58). This type of contact has the potential to go beyond bodily or mental interaction and reach out and touch the spiritual sense or the soul. This transpersonal relationship can then release strength for the person to gain inner harmony within the mind, body, and soul and generate self-healing.

Review of Relevant Research

Surviving a BMT represents a major victory against malignant disease but also creates challenges of survivorship for patients and health care professionals. Although prospects for long-term survival following BMT

have increased, there is still little known about the psychosocial quality of this survival. Existing research on clinical outcomes following BMT has focused almost exclusively on mortality and disease morbidity. There have been approximately four major studies published regarding the psychosocial and psychiatric aspects of BMT. There is evidence, however, that survivors experience significant psychosocial, spiritual and psychological changes from the BMT procedure. These changes appear to be the result of the physical complications of aggressive treatments, the stress of being near death and the effects of being labeled a cancer patient (Baker, Curbow & Wingard, 1991).

Wolcott, Fawzy and Wellisch (1986) identified major psychosocial themes of BMT. They are:

- (1) BMT is a procedure associated with very high physical and emotional stress levels for recipients, family and team members;
- (2) very intense relationships develop between the BMT team members and recipients and their families;
- (3) there are definable psychosocial as well as medical phases of BMT;
- (4) liaison psychiatrists who become fully integrated members can help lower the level of distress and promote effective coping;
- (5) the major psychiatric knowledge useful in the BMT setting includes the psychosocial phases of treatment,

psychological stress responses, coping and adaptation, and (6) recommended liaison BMT service include the therapeutic relationship to discharge; and (7) the donation appears to be living-related kidney donation. Themes are consistent with aspects of cancer.

Literature describing BMT is often limited in generalized that psycho the transplant process. identified. These stages undertake a BMT; (2) the conditioning regimen; (3) germ-free isolation; (4) engraftment; and (6) hospital treatment.

According to Haber, undergoing a BMT may be full of ambiguity. Nurses can help patients and families

factors that surround the decision and the lingering ambivalence that may persist after the decision has been made. Uncertainty is also a hallmark of the preadmission outpatient phase of treatment. Nurses can provide information about the sequence and timing of diagnostic tests. If admission to the hospital is delayed, then the clinical interpretation of the delay should be offered explicitly and repeatedly to the patient. Haberman believed that the nurse faces the dilemma of how to support the patient's hope and belief that a cure may still be possible, while also being sensitive to the patient's readiness to hear and comprehend bad news. Further research is needed to document the variety of psychosocial factors that influence patients' adaptation to the entire transplantation process.

Baker et al. (1991) presented results of a follow-up survey of 135 BMT survivors at the John Hopkins' Oncology Center. The primary purpose of this study was to survey the valued roles and the quality of life of long-term survivors of malignant illness treated by BMT. The criteria used for patient selection to participate in the study included: (1) 18 years of age or more; (2) six months or more post BMT; (3) had received allogenic, autogenous or syngene transplant; and

(4) not in a life-threatening relapse.

Data were gathered by means of a self-administered questionnaire. A general role inventory was modified for the purpose of serving as a measure of the extent to which survivors were able to maintain pre BMT roles. The checklist consisted of questions concerning ten basic roles that an individual may perform. The respondents were asked whether they performed each of these roles before BMT and whether they were currently engaged in performing the roles following the BMT. In addition, a quality of life outcome measure (life satisfaction and psychological adjustment) and the Satisfaction with Life Domains Scales (SLDS) were administered to the BMT recipients.

The following summarized the changes that recipients reported with regard to role performance before and after BMT. Persons are categorized on each role as either (a) never having had it; (b) having the role before BMT but not after (lost); (c) not having the role before BMT but having it after (gained); or (d) having the role before and after BMT (retained).

The ten roles consisted of student, worker, volunteer, caregiver, home maintainer, friend, family member, religious participant, hobbyist/amateur and participants in organizations. Although all of the

roles increased in importance to some extent, the most important roles identified by the patient subjects were: (1) family member, (2) caregiver, (3) worker, and (4) friend. Additionally, a series of t-tests were applied that examined differences in importance. The results revealed statistically significant differences in increased importance of the worker ($t=-2.42$, $p<0.05$), home maintainer ($t=-3.55$, $p<0.01$), friend ($t=-2.65$, $p<0.01$), and family member roles ($t=4.72$, $p<0.001$).

The second part of the study applied a series of Pearson Correlation Coefficients to examine the relationships of role retention or loss to the quality of life of BMT survivors. Role retention was measured by a simple count of the numbers of roles retained during the BMT period (and as a weighted summary of each role retained by its importance). As predicted, role retention was significantly related to quality of life as measured by the Satisfaction with Life Domains Scale ($r= .34$). Participants were then asked what effect their illness had on their job plans—none, slight, sizeable or great. In all cases, persons whose illness caused a great deal of impact on their job plans had the least satisfactory quality of life. The study also examined the quality of life between men and women. For men, the loss of the work role was

correlated at a statistically significant level ($r = .43$). This finding, however, was not found for women. In discussion of the study, it was apparent women survivors of BMT were less affected by associated role losses than men. The researchers concluded that this finding was the reflection of women being better able to continue certain roles despite illness, a greater flexibility in role adaptation, or a greater dependence for men on their role activities in order for them to feel satisfied with their lives.

It is difficult, however, to draw conclusions of how BMT survivors maintain valued roles and how they adapt and survive the experience from this research or previous studies due to the design limitations and small sample sizes. Additional research questions recommended by Baker et al. (1991) focused on the importance of personal meaning in coping with stressful life experiences, and how the illness experience affects the type of coping used.

Andrykowski, Henslee and Farrell (1989) interviewed twenty BMT survivors and found that the survivor's level of functioning varied greatly. The study was intended to document the physical and psychosocial functioning of survivors of BMT. Criteria for participation in the study were (1) 18 years of age or older and (2) living

at home for at least two months following BMT. All the patient subjects completed the Profile of Mood States (POMS) and the Functional Living Index-Cancer (FLIC). The POMS is a 65 item adjective checklist. The FLIC is a 22 item self-report inventory used to assess the overall functional quality of daily life of patients with cancer. In addition, patients were asked (a) whether they would still decide to receive a transplant if they had it to do again and (b) the extent to which their course of transplantation and its sequelae corresponded to their pre-BMT expectations.

No significant correlations were found between age, sex, education, presence of chronic or acute graft verses host disease or dose of total body irradiation received and overall or subscale scores from the FLIC or POMS. Time since transplant was found to be marginally associated with the emotional functioning factor on the FLIC ($r = 0.36$, $p < .10$) suggesting that emotional status improved with time. Age at transplant was significantly associated with total current functioning ($r = .40$, $p < .05$) and physical functioning ($r = 0.46$, $p < .10$), suggesting that younger patients evidenced less fatigue and better overall functioning following BMT.

The study found greater mood disturbance on the POMS relative to other samples suggesting that emotional

readjustment may pose a greater challenge for BMT survivors than is currently recognized. The results indicated that post-BMT physical and psychosocial functioning varies considerably among BMT patients.

Respective of functional status and expectations, however, only one patient indicated that he would not make the same choice again to undergo BMT. Future study in the area of understanding why patients differ in functional states after BMT is needed to help patients to resume a normal, productive life.

Another study was conducted by Ferrell, Schmidt, Rhiner, Whitehead, Fonbuena and Forman (1992). The purpose of the study was to explore the concept of quality of life for BMT survivors to gain understanding of nursing interventions that may improve quality of life in this population. This qualitative study consisted of a one-time interview of 119 BMT survivors using six open-ended questions. Selection criteria included (a) the BMT had been performed a minimum of 100 days previously, and (b) subjects had to be 18 years of age. Data were collected with two instruments: a demographic data tool and the BMT-Quality of Life Survey (BMT-QOLS). The six survey questions addressing quality of life (QOL) included:

- (1) What does the term QOL mean to you?

- (2) How do you think that BMT has affected your QOL?
- (3) What makes your QOL better?
- (4) What makes your QOL worse?
- (5) What do you think that the physicians and nurses could do to improve your QOL?
- (6) Are there other thoughts you would like to share about your experiences as a BMT patient or about QOL?

Content analysis was performed on the written responses to the six questions. Researchers independently analyzed the data for themes. The most frequent themes of the responses of question 1 were being healthy, having a heightened appreciation for life, having family and relationships, being normal, being satisfied and fulfilled in life, being able to work, and being independent. The responses from question 2 identified that having a second chance as a major theme, as well as the opportunity to improve QOL, increased appreciation for life, number of side effects, spirituality heightened, and strength and stamina decreased. Responses to the third question indicated having good health and having family and friends as very frequent themes. Other themes to question number three were being alive, having a positive attitude and peace of mind, having a job, being able to enjoy life and having goals. The responses to question 4 described

experiencing physical losses as the most often theme. Other themes were being psychologically distressed, having unfulfilled goals, losing relationships and being financially distressed. Responses to question 5 identified being accessible, reinforcing current education, providing support groups, patient participation in decision making, discovering a cure and providing additional coping strategies as the key themes. Responses from the sixth and final interview question were integrated into the analysis of the first five questions.

Based on the responses to the five questions, the total analysis indicated that BMT survivors valued health as the major factor. Respondents perceived the BMT had a positive impact on QOL by giving them a second chance. Negative consequences of QOL included problems such as side effects from treatment and the constant potential for recurrent illness. Patients facing a decision to undergo BMT often felt that they had little choice or control because BMT was often the only alternative to death. Future research recommended from this study included using in-depth methods with smaller samples in order to explore the existential meaning and experience of transplant.

Two major questions were addressed in a study on

quality of life following BMT by Andrykowski, Altmaier, Barnett, Otis, Gingrich, and Henslee-Downey (1990).

First, does the post transplant QOL evidenced by BMT patients differ from that of a matched group of renal transplant patients? Second, what factors are associated in post BMT quality of life? With regard to the first question, comparisons revealed few differences between the groups. This research, however, argued that while BMT provided at least a reasonable chance of cure, the overall experience was not considered to be "normal."

Although some BMT patients reported an excellent, virtually normal life, other BMT patients reported less than normal status in a variety of areas such as relationships and family; being independent; being healthy; being able to work; appreciation for life; being satisfied and fulfilled with life; and being normal. According to this study, further research is necessary to identify means by which post-BMT QOL can be improved.

In 1991, Altmaier, Gingrich and Fyle compared BMT survivors to a matched sample of patients undergoing maintenance chemotherapy in four areas of function: physical health, including symptoms and physician visits; personal functioning, emphasizing ability to

The instrument is divided into three parts, consisting of questions related to pre-transplant, during transplant and after transplant. Examples of pre-transplant questions consisted of the following:

1. What was life like before your diagnosis of cancer?
2. What thoughts and feelings did you have after being diagnosed?
3. What treatment did you have at this time?
4. How did you arrive at the decision to have a BMT?
5. What could the health team have done better for you at this time?

The second part focused on during transplant and the following are examples of questions asked during this session:

1. Describe the procedure in your words.
2. What do you remember happened?
3. What helped you during this stage?
4. What thoughts, perceptions and feelings do you remember about this stage?
5. What could have been done to help you more during this stage?

The third part of the questionnaire involved post transplantation. The following examples of questions

patients and their families must be based on an understanding of the physiologic, psychosocial and spiritual aspects of transplantation in order to increase the significance and necessity to further research about the BMT experience. Nurses, who provide the majority of care for persons with BMT, may be in the best position to recognize the significance of patients' needs. Nurses are therefore mandated to investigate and develop interventions and support systems for the BMT survivor.

Research is lacking about the psychosocial, emotional and spiritual factors involved in BMT, either before, during or after treatment (Altmaier et al., 1991). Research about the psychosocial morbidity related to cancer diagnosis treatment and survivorship necessarily lags behind the medical advances already made. As aggressive treatments more frequently result in cure or prolonged remission, patients, their families and health professionals need to be more attentive to survival issues and the lived experience of these persons.

Summary

In 1979, Jean Watson proposed a Human Science and Human Care conceptual nursing model that emphasized human caring as an intersubjective process that

includes the nurse and client in a transpersonal caring relationship. This relationship can allow the client and nurse to find meaning of a health-illness experience. Although the review of the literature revealed a sharp increase in the performance of BMTs in the past decade, there has been little research on its effects on survivors, especially the psychological and emotional factors involved in BMT, either before, during or after treatment.

CHAPTER THREE

METHODOLOGY

The purpose of this study was to explore the perceptions of a BMT survivor regarding his/her lived experience. This chapter focuses on the methodology of the study and includes the following sections: the research design; the case study subject selection process; the data collection instrument; data collection procedures; and protection of human subjects.

Research Design

A qualitative case study design was employed to investigate the lived experience of one BMT survivor. A case study is an in-depth investigation of a single individual over time. This research design enables the researcher to conduct an in-depth analysis of phenomena in order to provide a holistic understanding and gain new insights.

Subject Selection

The subject was chosen from a private oncology practice. This practice consisted of five physicians with an active patient population of approximately 3000. The criteria used for the selection of the case study were as follows:

1. Received a BMT for potential cure of a diagnosed cancer.
2. Ability to understand English.
3. Consent to participate.
4. Post transplant for six months.

The selection of the individual was made by obtaining a list of the last five patients who had successfully completed the BMT process and was six-months post transplantation. The list was obtained from the University of Iowa transplant unit, which had been identified by the physician practice as its referral base for BMT. Only two of the last five patients were six-months post transplantation and of these two, only one consented to participate. Eligibility was then validated from the subject's medical record regarding the criterion of receiving a BMT for potential cure of a diagnosed cancer.

Data Collection Instrument

The data collection instrument utilized in this study assisted in obtaining descriptive information in five, one-hour face-to-face focused taped interviews containing general questions identified in the nursing and oncology literature. The questions served as a guide to direct the interview and facilitate in-depth discussions regarding the subject's lived experience.

for objective analysis and for the researcher to review her own biases, prejudices, and likes and dislikes relevant to the subject studied.

The interviews were conducted over an eight-week period. During this time frame, the subject was confronted with his mother being diagnosed with metastatic lung cancer to the brain and the disappointment of his own relapse of disease eight months following his BMT. The patient did not want to delay or terminate the interviews and requested that the researcher interview his wife in one of the six sessions. Although six interviews had been planned with the subject, only five were conducted due to the interviews lasting more than one hour. The subject identified that he believed his wife could complete some of the time gaps he experienced during the BMT.

The five interviews took place at the subject's home and a sixth one, per the subject request, took place at the interviewer's home where the subject's wife was interviewed. The subject also requested that his wife be allowed to quietly sit in the room during the interviews. The interviews lasted one hour and on occasion longer depending on the subject's desire to continue to share his thoughts, perceptions and feelings.

were asked:

1. How has this experience affected your life?
2. What concerns do you anticipate since this procedure?
3. In what ways do you look at life differently since the transplant?
4. What life goals do you have now?
5. What could the health team do for you now?
6. What other thoughts, perceptions and feelings would you share about your experience as a BMT patient?
7. What would you tell another patient about this lived experience?

Data Collection Procedures

Through taped interviews, the researcher and subject explored aspects of the BMT experience that were important to the subject. The interviewer's questions addressed the subject's thoughts, perceptions and feelings prior to transplantation, during and after the treatment.

Using a focused-interview format, the researcher attempted to discover patterns or themes and to understand the BMT situation as lived or experienced by the subject. All interview sessions were taped to allow

for objective analysis and for the researcher to review her own biases, prejudices, and likes and dislikes relevant to the subject studied.

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Protection of Human Subjects

Written permission to conduct the study first was obtained from the Drake Human Subjects Research Review Committee (Appendix A). Next, written permission was obtained from the subject's primary physician (Appendix A).

The subject in this study had the right to privacy, informed consent and the right to freedom from harm. A patient cover letter was presented to the subject describing the purpose of the study, the risks and benefits involved and the procedure to initiate the study. The cover letter also informed the patient that participation was voluntary and he was free to stop the interviews at any time. Also the cover letter informed him the study was confidential and that in no way would participation in this study affect his care (Appendix A).

The researcher then obtained a signed patient informed consent allowing the researcher to interview the subject about his thoughts, perceptions and feelings regarding his life before, during and after the BMT procedure. The consent form explained the number of interviews and allowed the subject to choose the location and time. The form also informed the subject that he had the right to refuse to answer any question

or terminate the interview at any point. The interviewer reinforced that the study would be confidential and have no greater psychological risk than those risks ordinarily encountered in daily life (Appendix A).

Summary

In order to explore the lived experience of a BMT survivor, a qualitative case study design was employed. Five one-hour taped interviews were conducted with a BMT survivor and data were collected that related to before, during and after transplantation. Chapter Four presents specific data that describe the subject and provides a sequential summarization of each interview session.

CHAPTER FOUR

CASE STUDY DATA

The purpose of this study was to explore the lived experience of a BMT survivor. Five one-hour taped interviews were held with the survivor. This chapter presents specific data that describe the subject and provide a sequential summary of each taped interview session.

Case Study Subject

The subject selected for this study was a 37 year old, white male. He is married, no children and lives in a small rural town. He is approximately 5'4" and weighs 115 pounds. He works in a professional role in marketing and has a Master's degree in Recreation. His wife and he have lived in a small rural community of a Midwestern state for the last three years.

The subject was originally diagnosed with duodenum cancer in September of 1990 in the state of Maine. At this time, he experienced a rapid onset of abdominal pain, anorexia, jaundice, weight loss and gastrointestinal bleeding. He presented to the health care team of Maine in a very critical state. A lesion was biopsied from his duodenum and given the pathology report of adenocarcinoma. For approximately three

months, he received chemotherapy with synchronous (radiation) therapy. The medical records from Maine indicated his prognosis was adverse and the medical team indicated treatment was for palliative measures. He continued treatments through October and November of 1990, with a surprising positive response to the chemotherapy and radiation therapy. At this time, the subject and his wife were facing job displacement and decided to relocate to the Midwest for job opportunities.

In July of 1991, the patient was admitted to the hospital with a potential infection and presented with neck lymph node enlargement. The nodes were biopsied and the pathological report concluded T-cell lymphoma. There was some concern by the physicians that this perhaps may have been the original diagnosis in Maine of 1990. The subject then underwent a new regimen of chemotherapy. As part of this regimen, in August of 1991, the patient went to the University of Iowa Hospital and Clinics for BMT evaluation. The University Hospital and Clinics recommended that because of the patient's low tumor burden, he would continue with chemotherapy and prepare for bone marrow harvesting in case of the need for a BMT in the future. He was admitted to the University hospital in December, 1991,

for the bone marrow harvesting.

The patient continued to work throughout his chemotherapy and until June of 1992, his life was pretty uneventful. In June, 1992, the patient experienced a recurrence of his lymphoma to the right groin lymph nodes and in July underwent a BMT.

The patient's BMT hospital stay lasted from July 20, 1992, to September 20, 1992. He experienced the typical side effects from a BMT, such as nausea, vomiting, diarrhea, temporary hair loss, mouth and throat sores, skin irritation, bladder irritation, liver problems, heartbeat irregularities, breathing problems, infections and the severe complication of gastrointestinal bleeding.

Sequential Summary of Interview Data

The five interviews took place at the subject's home with the sixth one at the interviewer's home per patient request. All the interviews took place at approximately 4:00 to 5:00 p.m. The subject selected this time because of the convenience as well as the need to eat early as a result of digestive problems from radiation therapy.

The detailed verbatim interview data from the five taped interviews summarized in this section can be found in the Appendix B-F. The sixth interview with the

subject's wife is not contained within the Appendix because the research questions were pertinent to the BMT survivor's thoughts, perceptions and feelings.

The first interview (Appendix B) involved reviewing the purpose of the study, consent form and the patient's rights. The interviewer wanted to be certain that the subject understood each of these before proceeding. This meeting focused on establishing rapport and a review of possible questions that the researcher would ask. In addition, the subject was reassured there would be no right or wrong answers. The subject also requested that his wife be able to listen to the interviews.

The interviewer and subject were comfortable with their nurse/patient relationship but both identified some unfamiliarity with interviewee and interviewer roles. The interviewer and subject have been acquainted on a professional basis. The interviewer was a nurse within the practice that the subject sought his oncology care, as well as providing nursing care to the subject before and after his BMT. Both hoped this would be a positive experience and looked forward to what new relationship might develop from this study. The remainder of the first interview involved a review of the subject's medical history as described by the

subject. The subject was questioned about how he felt at the onset of his disease and he clearly reinforced several times little memory of this phase because of being so sick. The interviewer realized on the completion of this interview that it was going to be difficult to keep on the topic of "before" transplant. It seemed the discussion returned frequently to the present and future.

The second interview (Appendix C) took place one week after the first interview. Once again the interviewer reinforced this session would focus on what the subject had experienced before the BMT. At this meeting, the subject had just learned of his mother's recurrence of lung cancer to the brain. The subject immediately referred to this and at this time the interviewer and subject conversed without the tape recorder per the subject's request. The reason for this related to the subject's need to ask some medical questions related to his mother's cancer.

The interview resumed beginning with the subject and his wife's arrival to the Midwest. One of the key points the subject discussed was the relationship of stress to disease. He perceived he had been having chronic stress for approximately two years prior to his diagnosis. "I believe the stress in a relationship with

my supervisor in Maine was the open door for the cancer." He also shared strengths about himself that he was not consciously aware of prior to his diagnosis. For example, "apparently my illness and the way that I have handled it has served as an inspiration to people and I was elected to the Girl Scout Hall of Fame two weeks ago." He recalled that he had a very positive attitude about his original diagnosis and believed that he did not think about dying. He talked about crying, yet he did not interpret this response as a negative feeling. He referred to his philosophy about stress factors on several occasion and shared what techniques he was using to control stressors in his life now.

The remainder of the second interview discussed his thoughts and feelings about making the decision to consent to the BMT and how he perceived that he was adequately prepared for the procedure by the health care team. The last concern the subject shared involved the financial burden this procedure created and how he was handling the financial issue.

The third interview (Appendix D) involved the subject's thoughts, perceptions and feelings about the BMT procedure, itself. One of the main points he identified that he learned was realizing the chemotherapy a patient receives prior to the transplant

leaves a much larger impact on the patient than the actual BMT. "It (transplant) was just an IV, the suffering was from the lethal side effects of the chemotherapy."

The third interview also focused on the physical layout of the unit and the restrictions of the unit. He spoke about the isolation and feelings of loneliness. "I didn't really look forward to people visiting. The only times that I felt lonely was when I knew [my wife] was over here in town and not here." This session also dealt with how the patient felt about the quality of health care received at the hospital. He identified all the different side effects he experienced and his feelings about them, and once again returned to his stress philosophy. He also believed that due to his poor medical state he had few thoughts beyond his physical needs during the BMT procedure. At this point, the subject believed his wife could better fill in the gaps of during the procedure. Though the purpose of the study was to interview a BMT survivor, it was decided that the last interview would be with his wife to allow actual information regarding the time during the procedure if needed.

The fourth interview (Appendix E) explored with the subject his thoughts, perceptions and feelings following

the BMT. The subject at this time, however, experienced a recurrence of his lymphoma in his axilla area. The subject requested some time to talk about this relapse instead of our planned interview. This meeting lasted approximately one and one-half hours. The subject shared his feelings about finding the lump and what the waiting was like during the night while waiting to call the physician the next morning. The interviewer and subject talked about the power and comfort the subject's physician and staff gave him, the possible treatment options, and his need to see his mother.

The subject then returned to explaining his medical follow-up care from the health care facility and again the conversation moved to the subject's positive thinking and stress philosophy. He discussed his feelings on the day of discharge and "leaving the womb fear." The session then addressed his feelings with regard to how the BMT had affected his life. "I think having cancer has affected my life more than the transplant did." The remainder of this interview focused on what the subject would tell another patient about the BMT procedure in addition to what the health team could have informed the subject about prior to the BMT.

The last interview (Appendix F) with the subject

The interview then focused on the subject's thoughts and feelings about his own disease, his cure and his responsibility in his care. He expressed how little control patients have when hospitalized and how staff could support allowing the patient more control when possible. He shared the differences about himself now as compared to before the transplant and how he believes other people see him now. He concluded this interview by expressing what things and people have helped him to live through the BMT process and how he perceives his future since the recurrence of his cancer. During this interview the subject also expressed his thoughts and feelings about intimacy with his wife. The final interview concluded with a discussion of the subject's current stressors and coping ability.

The sixth interview that was conducted with his wife reinforced the thoughts, perceptions and feelings of the subject. The remainder of the interview allowed his wife to express some of her own thoughts and concerns regarding the BMT procedure.

Summary

The diagnosis of cancer and the complexity of a BMT procedure elicit many different thoughts, perceptions and feelings about oneself and life. This chapter presented specific data that described the subject and provided a summarization of each interview session. Chapter Five will analyze and discuss the findings of the interview data and the significance of the findings for advanced nursing practice.

CHAPTER FIVE

ANALYSIS, DISCUSSION AND RECOMMENDATIONS

Analysis

The purpose of this study was to explore the thoughts, perceptions and feelings of one BMT survivor regarding his lived experience. This chapter will analyze the interview data for repetitive ideas and conceptual themes, discuss the findings of the study and identify the significance of the study for advanced nursing practice.

Three research questions were developed for the study: (1) What thoughts, perceptions and feelings does a BMT survivor have regarding the lived experience of the BMT procedure? (2) How does one BMT survivor perceive the BMT procedure has affected his/her quality of life? and (3) What interventions and support measures would a BMT survivor recommend to health care professionals to enhance the care received? To answer these questions, analysis of the data from five one-hour taped interviews were categorized by repetitive ideas and into conceptual themes.

The first research question was: What thoughts, perceptions and feeling does a BMT survivor have regarding the lived experience of the BMT procedure? In exploring this research question, the interview data

were analyzed and organized according to the thoughts, perceptions and feelings that were repetitively identified by the subject. Four conceptual themes were formulated to categorize these repetitive thoughts, perceptions and feelings. They included spiritual, psychological, physiological and social. In the following paragraphs, each conceptual theme will be described and examples of the interview data will be listed in sequence of occurrence.

The first conceptual theme that categorized this survivors thoughts, perceptions and feelings was spiritual. One consistent repetitive feeling that influenced his spirituality was hope. Hope encompassed wanting and believing in options for cure. Planning for the future and having a positive attitude were interventions he utilized to keep his hope alive. His positive attitude, however, was influenced by his realism of life. He believed a logical positive attitude could affect his outcomes but he did not believe he could magically will things to change or go away. The spiritual theme also included his beliefs and values. Having survived the BMT seemed to have resulted in alterations in his beliefs. Simply being alive encouraged him to live life to its fullest and to "go for it". He also had a desire for leisure

activities and described intense feelings for enjoying the "little things" in his life. He began to prioritize and clarify his values and focus his energies toward family, friends, work and health. In other words, this survivor began developing and enhancing his philosophy for living. Examples of interview data to support the spiritual conceptual theme are:

"I have been reading Bernie Siegel, which I am not a big fan of, but I do use his meditation tape."

"I try to prevent self talk. That's where the key is in stress management for me."

"I never wasn't in a positive mood. And, I guess maybe that was a depth of myself that I didn't know I had."

"I just assumed I was going to get well. That was just the attitude I had."

"...they said, well think positively about whatever it is that's wrong. And I said, where do you draw a line between optimism and realism?"

"And, I don't honestly believe that if I think real positively about this thing in my arm, that if it is lymphoma, I am going to turn it into infection. I just don't believe that. All I can do, I think, is just think positively about it and handle it. I am not going to waste time trying to think it into something that it is not. So, you know, I think I am a fairly positive thinker, but it is in terms of problem solving, not in terms of moral or whatever."

(Regarding recurrence) "Would I be able to go to my conference? Would this affect my trip to Florida? Would this affect my trip to St. Louis? Would this affect my vacation...? You know, I thought in terms of the things I am looking forward to and what it might do."

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"...especially with the recent physical situation, I am simply not going to confront it or deal with it in a real direct way. It is just not important to upset me."

"As long as I have my relative health and as long as I have my wife, friends and family, that is what is important."

"...it is important to me to be true to myself and to be accurate."

"I guess I have never really believed in the philosophy of one day at a time. My belief is more expressed as plan things for the future because that is a magnet that draws you into the future, so make plans."

"I don't fight cancer, I don't battle cancer. I live my life."

"Cancer is part of it right now, but it is not my focus. It is something I have got to deal with."

"People could say, 'Yeah, but you had seven months of cancer-free life.' Right, but for half of that time I wasn't functioning very well. Where does quality of life come in here?"

"I never ever let a doctor tell me what my chances of survival were or what my prognosis was. And I am real glad, because if I had believed what they (physicians in Maine) had told me about the adenocarcinoma, I might have believed them and died."

"The thing that bothers me the most quite bluntly, is if they didn't get it and if it does recur, as far as I know, there is very little else they can do."

"And then it recurred, he told me recently that he really felt like they got it with the transplant. I said... you told me once before I was cured. So I have some doubts this time."

"I have very little faith right now. I have been told by too many doctors now that I am cured on too many occasions, and I have developed a very

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cynical attitude about that. Talk to me in ten years, maybe I will believe it then."

The second conceptual theme that unfolded from repetitive thoughts and feelings was categorized as the psychological theme. The first and foremost powerful feeling of this theme was control. The subject, who was a person used to being the person in charge, taking care of himself or being the person whom others depended on, found this emotional uncertainty very difficult to cope with. This altered sense of control was confusing and frightening, causing him to feel powerless at times. Another consistent thought this survivor expressed was stress. He described stress as the inability to handle problems constructively, to resolve his conflicts creatively, and to manage his anxieties. He strongly believed that stress may have contributed to the beginning of his illness. He also realized that stress would be part of his life but he was most concerned with how he was managing his stress.

His fear of recurrence of the cancer also was characterized in the psychological theme. In the decision to consent to the BMT, the subject believed that the procedure would remove the chance of his cancer recurring, yet he always continued to fear recurrence even after the BMT. Feelings of returning to normal

also were repetitive in this psychological theme. Leaving the hospital resulted in ambivalent feelings of excitement and dismay. The subject was glad to leave isolation. On the other hand, he identified that losing the "safety net" of the hospital could be frightening. According to the subject, recovering from the BMT was a slow process that resulted in desperate feelings to get well. As a result of this need to get well, the subject began to explore prioritizing and accomplishing his goals. The last repetitive feeling in the psychological theme was the subject's desire for knowledge. He believed information and knowledge expanded his ability to understand what was happening, which also gave him a sense of control to make informed decisions. Examples of interview data to support this psychological theme are:

"I wasn't that active (in his care) in Maine, and I don't think the doctor there would have encouraged it."

"I believe the stress in a relationship with my supervisor in Maine was the open door for the cancer. I believe that very strongly..."

"Continued severe stress, not short-term."

"And I said, 'Well, I am sure she (his wife) won't want to do that because we won't have time to do that.' But of course, she went, while I sat in my room and stewed. And I understood that mentally, but emotionally I wanted out of there."

"I am much more aware of the central theme of stress more that I used to be."

"Above the bulletin board was a TV and VCR which was impossible for me to reach without help. That was frustration."

"I am trying to take control of an office situation, so I talked to my boss... She gave me some tapes (Leadership Secrets of Attila, the Hun, by Wess Roberts) on how to deal with difficult people, so I can learn some techniques to deal with a difficult person in my life."

"I didn't think I had any option."

"But I can't find it in myself, in all honestly, to grieve for my mother yet. And I'm wondering if there is something wrong with me, quite frankly, in that I am not grieving for my Mom and I am not really upset. I am upset, but not to the point of being bothered by it."

"It would be my third recurrence...It was really kind of devastating when I found the lymph node."

"I really like the fact my doctor here listens to me and it is almost scary sometimes, because I come in with a theory about something, a symptom, and they believe me...I feel like I have taken a very active role in my treatment.."

"I didn't learn enough about the transplant before I did it. So I went in kind of blind."

"Because if I have knowledge, I am a much stronger person. So I just wanted to know what exactly was going to happen to me."

"I wish that I had had the book that I mentioned for the BMT because it is in lay language."

"...I was amazed that the amount of information I got in the eight weeks from the nurses because they were not at all reluctant to tell me what was going on. If I didn't think what they told me was right, I would ask the doctor. But I didn't always think that what the doctor was saying was right either.."

CHARTER LIBRARY

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"[The physician] knows me pretty well. He said, 'You really do a lot better when you know what is going on.' And that is true. If I know what the situation is, I can mentally deal with it. It is the unknown that scares the heck out of me."

(Regarding the day of discharge) But it was rainy, wet, and cold day. It was beautiful the day before. And I got discharged on this horrible day."

"Just the stress of having a doctor come in the morning and saying are you ready to go home, and me saying yeah, I am. That was stressful in itself."

"So it was my decision to discharge, with his (doctor) concurrence of course. It was just very emotional."

(Regarding anxiety in leaving the hospital) "You know, when you are there for nine weeks in the womb, so to speak. And your every wish is catered to, it is scary."

"I have decided that when I get back up to 115 lbs....then I am going to start doing some of my workouts."

"I was elected to the Girl Scout Hall of Fame."

"I will probably if everything is okay this fall. I will be teaching photography again."

(Regarding goals after recurrence) "Because I had let myself start looking forward to... and now this is threatening it..."

The third theme of the survivor's thoughts, perceptions and feelings was categorized as physiological. This theme focused on the impact of physical changes that resulted in losses of daily activities. For instance, some side effects of the high-dose chemotherapy a patient undergoes prior to

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transplant, as well as post-transplant medication and the complications, can be physically stressful. Decreased stamina and limited activities reflect diminished physical strength. This subject repetitively identified his goal of returning to his physical state that he had prior to the transplant. The subject's limited digestive tolerance, inability to maintain his weight and retain his food were physical changes that he had to cope with on a daily basis. His nutrition was a thought that consumed much of his physical, as well as psychological themes. Many of his physical losses also affected his body image. His body gave him a sense of self, and these internal and external changes were very important in terms of the way he thought about himself and how he believed others perceived him. Examples of thoughts and feelings that support the physiological theme are:

"The chemotherapy had more of an impact on my body than the actual transplant."

"I had giant water blisters all over my body... and I peeled like crazy, and that bugged the heck out of me because I was picking away at my skin."

"The worst part of the whole thing for me was the urinary catheter that they put in. I hated that, absolutely hated that."

"Most of my suffering was from the side effects from the chemotherapy, especially later on."

"I have never been real self-confident in my appearance, and I elected not to wear a wig, but I hated the hair loss."

(Regarding his hair loss if more chemotherapy was needed) "I would be real discouraged. I really thought that I was done with chemo. If I had to lose my hair again... If I have to go through chemo, I want to make sure that it is going to do something worthwhile, especially if I'm going to lose my hair."

(Going home after BMT) "I can't remember when I've been that tired before."

"I was in excellent physical condition when I became ill. Which is one reason I think I came through it, the last 2 years."

"There was an exercise bike in my room for awhile. I hardly ever used it."

(On pass during BMT) "I sat while she shopped. At the end we saw a little wheelchair cart that would have been perfect, because I could have gone with her."

"I'm still not the morning person that I was. I would think nothing of getting up at 4 or 5 a.m. and going to work."

"I used to be in the habit of every morning, no matter what, I would get up and exercise, and I am out of that habit now. It is horrible."

"...the radiation that I received has damaged my stomach, and so now I have dietary restrictions."

"As long as I don't throw up, it really what it comes down to."

"I was on a liquid diet. Dr. Gingrich maintained that my bleeding started because I ate some honey roasted peanuts...That worried me for awhile."

"I hated the nocturnal feedings."

"When I get to 115 lbs....I don't want it to go to fat."

"One of the things I want most is to go to Minneapolis to the convention in the fall, looking as I do now, or at least as good. I do not want to go there without my hair."

"I don't know, it's not my body anymore. It is not the same one I grew up with."

The last theme with recurring thoughts, perceptions and feelings by this survivor was a social theme. This theme included roles and relationships, isolation, appearance and the desire to be useful and productive which were important in providing for his family's needs. Physical appearance and how others viewed him was clearly important to this survivor. Changes in his appearance made him feel self-conscious. Another strong feeling he expressed related to the social theme was having a job, money and insurance. The most intense feeling in this social theme, however, was his feeling about relationships. The social connections for this BMT survivor were the ability to give and receive support from family, friends and health care professionals. Isolation, or lack of social connection, made the survivor feel lonely. The final thought related to this theme was intimacy. Intimacy was related to feelings of a sense of caring and comfort from others. This survivor expressed intimacy as a sense of closeness and affection. Examples to support the social conceptual are:

"You know, I was really in good shape."

"I lost my job (in Maine) because of the illness."

"We could be hit for probably as much as \$10,000 and it is a scary, scary thought."

"The thing that has complicated things this last year is that our income went down by \$20,000."

"I will pay as much as I can, but I am not going to disrupt my life for that."

"We were very fortunate to have BCBS of Maine, and we had a very strong policy."

"No one with colds..."

"I couldn't leave my room until my counts reached 500 on the WBC."

"Three (visitors) at a time, max."

"No little kids."

"I like the fact that he is a touchy, feeling doctor."

"The office represents treatment, warmth and love."

"You know Pat gave my hand a little shake when I went by, no... I didn't feel... You know, I felt concerned interest at that point."

"The only time that I was really lonely was when I knew [his wife] was over here in town someplace (their hometown) and not here (hospital). And that is when I felt lonely."

"You know, I looked forward to see who I was going to get that night. Because that is really when I had a lot of contact, because [his wife] was there during the day and she left about 9 p.m. so I would be on my own after that."

"It wasn't a burden for her (the night nurse) at all to do that. And she just talked, we just talked a little."

"You know, (first day home after BMT) I got home the first night and [his wife] informed me that she thought she was coming down with a cold... so I called the doctor, 'can [his wife] sleep with me tonight? I have been looking forward to this for about nine weeks, not for anything sexual, but just for companionship."

"She (the day nurse) was the one person that made me feel empowered."

"It involves the feelings of being close with someone. I have to admit I was so sick... relationships are not something I think about... You might say I am just now starting to look at a woman as a woman. Yet, the desire to want to be close or together has grown even stronger than before and that is what I focus on."

"You know I chose [his physician]... He shakes hands, hugs and that kind of thing."

The second research question involved exploring how one BMT survivor perceived the BMT procedure had affected his quality of life. He believed having cancer affected his life far more than the BMT procedure. The transplant to him was merely one more very elaborate course in his treatment. He believed the fact that he "came through it" was partially due to his own internal fortitude and mental discipline. Since the BMT, he identified that he has begun to take more responsibility or control for infection precautions, such as washing his hands more often, being cautious around other ill people and immediately notifying his physician of any changes.

He also believed his underlying values and beliefs,

integrity and abilities had not changed a lot but that he had changed the superficial things in his life, such as not needing the full equipped camera to enjoy taking snapshots. His tolerance of friends and families also had changed. He identified that he had decreased his expectations of these relationships and stopped being so critical, especially of friends. He also believed he had begun to "loaf" more. He was not sure, however if this was a result of the BMT experience or a result of maturation. He identified that it took his illness to help him realize his self esteem had improved. He realized this by the support of his friends and colleagues. Another change in his life he identified was that he began to attend a community committee to substitute for the purpose of a support group. This type of social connection became an important outlet that helped him focus on life and living, not on his illness.

Finally the main action that the subject believed he had done to improve his quality of life was that he put his life in order. He had tried to leave himself on good terms with his friends, to write to friends and family more often and not to leave loose ends.

The final research question of this study was to identify what interventions and support measures a BMT

survivor would recommend to health care professionals to enhance the care he received. This survivor expressed the need for health care professionals to be accessible. There was a need to "be there" both physically and emotionally and specifically to be available for questions or to respond when problems arise. Much of the data indicated the need for information pre, during and after transplant. This information consists of the need for written and verbal materials about office and hospital routines, procedures, symptoms and the future.

The presence of caring support and counseling to enhance coping strategies was also clearly indicated by this survivor. He wanted information so that he could be involved in making informed decisions. Decision making was linked to maintaining control. One of the most significant examples provided by this survivor was the situation with medical staff not washing their hands to control his concerns with infection. Finally, the most important advice the survivor gave to health care professionals was the desire to have health care personnel who viewed him as a valued person to be cared for, respected, nurtured, understood and assisted through this experience.

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Discussion

The BMT procedure provides hope for many patients with cancer which was once thought an incurable disease. Contemplating the procedure and coping with the recovery phase is a trying experience for the patient and family.

The findings of this study are consistent with the limited work of previous researchers who have explored the concerns of BMT survivors. For example, Wolcott et al. (1986) identified major psychosocial themes of the BMT procedure. Physical and emotional stress, intense relationships, coping, loss and grief and social support were identified as psychosocial themes in the study. The results of the case study of this BMT survivor similarly identified physical suffering, roles and relationships, loss of control and social support as major conceptual themes of the BMT survivor. In this BMT study, having his job role, money and human connection with family, friends and health care professionals were repetitive themes. Baker et al. (1991) also studied roles and the quality of life of BMT survivors. They identified the most important roles as family member, friend and worker, similar to the findings of this study.

In comparing this BMT study to the one by Ferrell et al. (1992), similar themes were identified when

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exploring the concepts of quality of life. Similarities in findings related to being normal, relationships, side effects, strength, hope and finances. Both studies concluded these areas were affected the most in the survivor's life. The work by Haberman (1988) was particularly applicable to this study. This survivor validated themes common to BMT survivors identified by Haberman, including managing beliefs, managing recurrence and negotiating for control. As previously stated there is little research exploring BMT as a lived experience either before, during or after treatment.

The subject in this study expressed the importance of a caring relationship with family, friends and health care professionals. His wish for this type of relationship was expressed in all four themes and throughout the interview data. Being able to call his physician whenever needed, participating in decision making, being informed and providing a caring approach are examples of the relationship desired by this BMT survivor. Watson's (1988) Human Science and Human Care model proposes this same caring process between the patient and nurse. Watson's central focus on human care which addresses the physical, mental, spiritual and psychological themes of persons parallels the themes of

spiritual, psychological, physiological and social conceptual themes identified by this study. Realizing the perspective and subjective worth of the patient is a value exposed by Watson as well as a desired outcome by this BMT survivor.

Watson (1988) identified that the nurse must be able to express caring through various means, such as gestures, procedures, information and touch. This BMT survivor identified in the social theme that gestures of others and especially touch was important. Clearly the survivor in this study was looking for the health care professional to recognize his feelings and help the survivor express these feelings as in Watson's transpersonal relationship. Although the survivor believed he exhibited effective adjustment to the BMT procedure, there were identified themes he believed that health care professionals could have assisted with during and after this experience. This included his need for information, control, hope and caring relationships.

Human care requires knowledge of human behavior and human responses to actual or potential health care problems. As Watson's (1988) Human Science and Human Care model proposed, health care professionals have the knowledge and understanding of individual

needs, knowledge of how to respond to the person and the family's needs, knowledge of the person's limitations and strengths, knowledge of the meaning of the situation for a person, and knowledge of how to comfort with empathy and compassion. These were expressed desired outcomes for this BMT survivor.

Limitations

There are many limitations to any study of this type that explores the thoughts, perceptions and feelings of human beings. The first major limitation to this study that must be considered pertains to the sample size. The sample consisted of one male BMT survivor who was not randomly selected. The findings of this study may not be necessarily representative of other BMT survivors' thoughts, perceptions and feelings. Therefore, the ability to generalize the findings from this study is extremely limited.

A second major limitation of the study was related to the data collection procedures used. The primary data collection method relied on the interviewing skills of the researcher and the subject's ability to self-report his thoughts, perceptions and feelings. The concern of the researcher to avoid any additional psychological risk and the researcher's skill in interviewing may have limited some subject responses and

further exploration of sensitive themes. The subject's own ability to honestly disclose information, as well as being taped, also may have limited the data collected.

Another limitation relates to the analysis of the case study data. A qualitative case study design has no systematic rules for analyzing the data and presenting conclusions clearly. Because a case study also presents a subjective view, some conceptual themes and ideas may have been overlooked while others overemphasized in the data analysis. In addition, because of the interrelationships of any person's thoughts, perceptions and feelings, it is difficult to categorize the data into just one of the four themes.

The fourth major limitation of the study could be related to the researcher's bias. The researcher was familiar with the subject and may have consciously withheld exploring additional variables in consideration of the subject's feelings. Conversely, the researcher could have explored areas the researcher conceived to be critical in the BMT process. Also, the analysis of data may be somewhat influenced by the researcher's professional knowledge and experience about the BMT process. A final possible limitation in this study was the fact the subject's cancer recurred during the data collection process causing the need to explore those

feelings instead of his thoughts, perceptions and feelings before, during and after transplant.

Recommendations for Further Study

It must be recognized that research about BMT as a lived experience is in its infancy. As the ultimate goal of BMT evolves toward cure of an underlying disease as well as restoration of health, further research about the BMT experience becomes increasingly significant.

The first recommendation for further study is to replicate this study with another BMT survivor. This survivor might be a woman or from a different culture. The importance of this replication would identify whether similar thoughts, perceptions and feelings are experienced by subjects who represent a different gender and ethnic background.

The study should then be replicated with a larger sample size to examine if the conceptual themes are representative of the thoughts, perceptions and feelings of other BMT subjects. This study defined a BMT survivor as any person who was considered cured six months post BMT. Future studies should consider the definition of survivor as one year or greater to hopefully avoid a potential recurrence issue.

As conceptual themes are consistently identified by more BMT survivors, a conceptual schema can be created.

This schema or model can then be utilized to develop a survey or questionnaire which could measure thoughts, perceptions and feelings of BMT as a lived experience. As future studies increase understanding of why BMT patients differ in their experiences, the opportunity to use this knowledge in nursing practice, education, research and administration exist.

A final recommendation could examine the thoughts, perceptions and feelings of significant others. This would provide nursing with additional knowledge as to the priority concerns and lived experience of families of oncology patients as well as the oncology patients themselves.

Implications for Advanced Nursing Practice

Data from this study offer oncology nursing some new insights into understanding what a survivor of BMT experiences. It also increases awareness that the oncology nurse is the health care professional in the best position to influence quality of life for individuals with cancer. Although oncology nurses possess a wealth of knowledge and skill in the management of cancer-related problems and treatments of side effects, understanding the impact of the BMT procedure as a lived experience needs further attention. Assessment of the spiritual, psychological,

physiological and social conceptual themes can direct the establishment of many important goals in the provision of comprehensive health care for the BMT patient. Awareness of a BMT survivor's thoughts, perceptions and feelings can lead to changes in the current medical and nursing protocols across all phases of the transplant process.

Spiritual, psychological, physiological and social themes have provided a major source of content to be applied in nursing clinical interventions, education, research and administration to enhance the lived experience before, during and after the BMT. These themes can serve as an important foundation for current and future nursing practices.

A major implication for advanced nursing practice to better prepare BMT patients involves providing client education. Nursing will need to be honest with the information, yet try not to overwhelm the patient. The nurse should share information and education in manageable increments to enable BMT patients to reflect on the information, ask questions and absorb it. The educational materials and information also must be given to patients and families in ways that a lay person can understand the complex information. As nurses remember

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to explain all procedures and terms in a simple, nonthreatening way, the patient will be allowed a sense of control and decrease unknown fears. When nurses discuss risks and rewards of the BMT procedure with patients, place the information in perspective, and are sensitive to the fact that patients worry about simple needs such as pain, infections and other side effects, desired nursing outcomes will result.

When nurses share information, they should not underestimate the importance of asking the patient what information he or she would like. In this study, this survivor expressed the importance of not receiving facts and figures but the desire for information about options and hope. Nurses must not stereotype the information but tailor this knowledge to each patient on an individual basis.

The survivor in this study expressed the need for a basic manual that explained office and hospital policy and procedures. Although a manual was available the subject did not receive one. This points out the need to make certain that each patient be asked if he/she has received the manual.

The subject also identified that one of the important interventions that health care professionals,

friends and families could have done for him was to "be there." Implementing a caring consciousness during every nursing interaction will help to actualize human caring actions desired by patients. Nursing staff that are compassionate and accessible to both the patient and family is invaluable. This survivor expressed wanting a relationship that promoted and conveyed a sincere personal interest in him as a person.

Nights were an especially stressful time for this patient and was a time when he also felt most isolated and lonely. He communicated how he looked forward to finding out who his night nurse would be. He expressed that a nurse who shared a caring relationship during the night was extremely important to his recovery. Frequently, patients are cared for by other health care personnel. Fear is often heightened during these periods as this survivor expressed when being transported in the bubble wheel chair and the staff not maintaining infection precautions. Having a trusted, caring nurse present during procedures could calm the patient and alleviate fear and stress. Nurses who reassure the patient that the nurse will be the patient's advocate and "be there" can provide a secure therapeutic environment for the patient and family.

In managing the central aspects of the BMT procedure, this subject emphasized being allowed to participate in decision making. This patient reacted with annoyance to persons who tried to "dictate" rather than tactfully encourage him to do necessary things he would rather not have done. Giving the patient a chance to assert some control over decisions can lessen feelings of powerlessness. Decision making was linked to maintaining control in what was perceived as an "out of control" situation. The more out of control patients feel, the more they attempt to control their surroundings. Caring nurses who allow the patient to change his own TV, decide when to bathe, when and what to eat, schedule his activities and post grafts to see results and progress of tests are essential. Nurses who practice the development of caring transpersonal relationships and explore what a patient's life was before the illness can provide insights into the patient's desires for involvement in decision making and being in control.

Physiological aspects of the BMT procedure are also are stressful. Temporary hair loss, nutritional restrictions, blisters and catheters were miserable memories to this survivor. Physical mobility and strength to this patient was associated with health and

well-being. Nurses who understand and implement interventions that explain these physical changes can enhance the patient's overall physical functioning. Often nutrition is handled from a medical therapeutic frame of reference. The goal of nursing should be to assure that the patient completes each phase of care with the best nutritional status and incorporate the most individualized applicable eating habits into everyday life. The nurse and the patient should endeavor to use creative approaches to dietary management as was evident for this patient in all his diet requirements. Though little can be done to curtail these physiological processes, reinforcing education, purpose, explaining symptoms and educating the patient about future physical changes can result in greater physical well-being and independence for the patient.

This survivor identified that every person's experience is different and no two patients go through the BMT experience in the same way. The cancer phenomenon needs to be developed according to each patient's unique experience. In order to establish this human caring relationship with the patient, practicing nurses will need to develop relationships with patients that require the nurse to commit to an ideal of the intersubjective human-to-human care process. The

oncology nurse, as the principal caregiver, can provide ultimate caregiving through the establishment of transpersonal caring relationships with all patients.

Clearly, a human science approach to health care is required for nursing practice now and in the future. The human care relationship will need to be integrated in nursing education. Nurses today are seeking to bring about a new consciousness of what it means to be a nurse, to be caring. Educational programs and educators need to develop curricula in which nursing and caring exist side-by-side within the techno-cure world. Nursing curricula can contribute to the human science of nursing by establishing a set of values, goals and methods about humans and science that will integrate caring into nursing practices and evaluate students' performance in human caring.

Nursing research will need to continue to pursue development of new knowledge in relation to human experiences in health and illness and make discoveries on how to develop human-caring relationships with individuals. Researchers need to recognize and value other ways of knowing and to find approaches that retain the human context and allow for knowledge about lived human experiences.

In today's health care institutions, a one-sided perspective of health care delivery systems and cost continue. Because of this perspective caring values of nursing have received less emphasis in the system. The concepts of human care are threatened by the technology, the machines and administrative tasks to meet the needs of the system. Yet, as this survivor repetitively stated, he desired and expected a health care professional who practiced with a commitment toward treating him with a caring approach and protecting his human dignity and humanity. Administrators will need to place emphasis on nursing standards, protocols and evaluations to incorporate these caring practices. Focusing on caring interventions from an administrative point of view can affect patient length of stay, distribute health care dollars more appropriately and positively affect patient outcomes. Today's health care consumer expect cost effectiveness, quality skills and competency as a basic entry level of a health care provider. Human caring as the mission statement of an institution will be the difference between just a center and a center of excellence.

The findings of a phenomenological study are not meant to be generalized. Nurses, however, may better understand the need for human caring in individuals by

looking at the lived experience of other BMT survivors. There is strong suggestive evidence from this study that patients are seeking much more than skills and competence. It is human caring that demonstrates knowledge and understanding of individuals' needs. It helps nurses respond to other's needs in a compassionate and empathetic way, as well as practice with sincerity, individuality and spirituality in a human-to-human relationship.

REFERENCES

- Aaronson, N. (1988). Quality of life: What is it?
How should it be measured? Oncology, 2(5), 69-74.
- Aaronson, N., Meyerowitz, B., & Bard, M. (1990).
Quality of life research in oncology: Past
achievements and future priorities. Cancer,
67, 839-843.
- Altmaier, E.M., Gingrich, R.D., & Fyfe, M.A. (1991).
Two-year adjustment of bone marrow transplant
survivors. Bone Marrow Transplantation, 7, 311-316.
- Andrykowski, M., Altmaier, E., Barnett, R., Otis, M.,
Gingrich, R., & Henslee-Downey, P. (1990). The
quality of life in adult survivors of allogeneic
bone marrow transplantation. Transplantation, 50,
399-406.
- Andrykowski, M., Henslee, P., & Farrall, M. (1989).
Physical and psychosocial functioning of adult
survivors of allogeneic bone marrow
transplantation. Bone Marrow Transplantation, 4,
75-81.
- Baker, F., Curbow, B. & Wingard, J. (1991). Role
retention and quality of life of bone marrow
transplant survivors. Social Science of Medicine,
32, 697-704.

- Belec, R. (1992). Quality of life: Perceptions of long-term survivors of bone marrow transplantation. Oncology Nursing Forum, 19(1), 31-40.
- Bloom, J. (1991). Quality of life after cancer: a policy perspective. Cancer, 67, 855-859.
- Calman, K. (1984). Quality of life in cancer patients: An hypothesis. Journal of Medical Ethics, 10, 124-127.
- Engquist, C. (1979). Can quality of life be evaluated? Hospitals, 53(22), 97-100.
- Ersek, M. (1992). The process of maintaining hope in adults undergoing bone marrow transplantation for leukemia. Oncology Nursing Forum, 19(6), 883-890.
- Ferrell, B., Grant, M., Schmidt, G., Rhiner, M., Whitehead, C., Fonbuena, P. & Forman, S. (1992). The meaning of quality of life for bone marrow transplant survivors: Part 1. The impact of bone marrow transplant on quality of life. Cancer Nursing, 15(3), 153-160.
- Ferrell, B., Grant, M., Schmidt, G., Rhiner, M., Whitehead, C., Fonbuena, P. & Forman, S. (1992). The meaning of quality of life for bone marrow transplant survivors: Part 2. Improving quality of life for bone marrow transplant survivors. Cancer Nursing, 15(4), 247-253.

- Ferrell, B., Wisdom, C., & Wenzl, C. (1989). Quality of life as an outcome variable in the management of cancer pain. Cancer, 63, 2321-2327.
- Folsom, T. & Popkin, M. (1986). Current and future perspectives on psychiatric involvement in bone marrow transplantations. Psychiatric Medicine, 4(3), 319-327.
- Gardner, G., August, C., & Githens, J. (1977). Psychological issues in bone marrow transplantation. Pediatrics, 60(4), 625-631.
- George, J., Ed. (1990). Nursing theories: The base for professional nursing practice (3rd ed.). Norwalk, Conn: Appleton & Lange.
- Haberman, M. (1988). Psychosocial aspects on bone marrow transplantation. Seminars in Oncology Nursing, 4(1), 55-59.
- Hengeveld, M., Houtman, R., & Zwaan, F. (1988). Psychological aspects of bone marrow transplantation: A retrospective study of 17 long-term survivors. Bone Marrow Transplantation, 3, 69-75.
- Hymovich, D. & Roehnert, J. (1989). Psychosocial consequences of childhood cancer. Seminar Oncology Nursing, 5, 56-62.

- Lesko, L. (1990). Surviving hemalological malignancies. The Biology of Hematopoiesis (pp. 423-427). New York: Wiley-Liss, Inc.
- Lin, E., Tierney, D., & Sladlmauer, E. (1993). Autologous bone marrow transplantation. Cancer Nursing, 16(3), 204-213.
- Marriner-Tomey, A. (1989). Nursing theorists and their work. St. Louis: C. V. Mosby.
- Ochs, J., Mulhern, R. & Kun, L. (1988). Quality of life assessment in cancer patients. American Journal of Clinical Oncology, 11(3), 415-421.
- Parker, M. (1990). Nursing theories in practice. New York: National League for Nursing.
- Selby, P. & Robertson, B. (1987). Measurement of quality of life in patients with cancer. Cancer Surveys, 6(3), 522-543.
- Sellers, S. (1991). A philosophical analysis of conceptual models of nursing. Unpublished Doctoral dissertation. Ames, Iowa: Iowa State University.
- Smith, K. & Lesko, L. (1988). Psychosocial problem in cancer survivors. Oncology, 2(1), 33-39.
- Smith, S. (1990). Tissue and organ transplantation. St. Louis: Mosby.
- Stegman, M., Duncan, K., Pohren, E. & Sandstrom, S. (1985). Quality of life: A patient's perspective.

ANNA Journal, 12(4), 244-247.

Stewart, S. (1992). Bone marrow transplants. Highland Park, IL: BMT Newsletter.

Watson, J. (1979). Nursing: The philosophy and science of caring. Boston: Little, Brown & Company.

Watson, J. (1988). Nursing: Human science and human care. New York: National League of Nursing.

Welch-McCarffrey, D. (1985). Cancer, anxiety, and quality of life. Cancer Nursing, 8(3), 151-158.

Wingard, J., Curbow, B., Baker, F. & Piantadosi, S. (1991). Health, functional status, and employment of adult survivors of bone marrow transplantation. Annals of Internal Medicine, 114, 113-118.

Wolcott, D., Fawzy, F. & Wellisch, D. (1986). Psychiatric aspects of bone marrow transplantation: A review and current issues. Psychiatric Medicine, 4(3), 299-317.

Wolcott, D., Wellisch, D., Fawzy, F. & Landsverk, J. (1986). Adaptation of adult bone marrow transplant recipient long-term survivors. Transplantation, 41(4), 478-484.

APPENDIX A
CONSENT FORMS

To be completed by the Investigator:

Date Submitted: December 08, 1992

Proposal Title: Bone Marrow Transplantation as a Live Experience

Investigator: Cheryl Blunck B.S.N., R.N.

Faculty research advisor (for student research): Sandy Sellers Ph.D., R.N.

Return to: Sandy Sellers

Name

422 Olin Hall

Street Address or Campus Office

Drake University

City, State, Zip if off campus

To be completed by the Human Subjects Research Review Committee Chairperson:

Date Received: 12/9

Decision:

- ☒ Approval, no risk
- ☐ Approval, minimal risk
- ☐ Approval, subjects at risk, but benefits outweigh risks
- ☐ No approval. Subjects at risk or proposal does not adequately address risks, benefits and procedures.

Reasons for Disapproval: Consent form should delete the term "anonymous" (see attached). Consent form should indicate that there is a small risk for psychological discomfort.

Suggested Changes: _____

Human Subjects Review Committee Chair: Steven F. Faux

Date: 12/16/92

Steven F. Faux (1992-1993)

10/5/90

Final Notification Form

Primary Physician Informed Consent

Name of Investigator: Cheryl Blunck R.N., B.S.N.

Title of Research Project: Bone Marrow Transplantation
as a Lived Experience

The purpose of this study is, using a case method to examine the thoughts, perceptions and feelings of one bone marrow transplant survivor regarding his/her lived experience with this procedure. Hopefully this will assist the health team to better recognize means to improve care of patients undergoing bone marrow transplantation.

The study will consist of six one-hour taped interviews over a six-week period.

_____, partner in Medical Oncology and Hematology Associates, agrees to participate in the stated study conducted under the supervision of Sandra L. Sellers, Ph.D., R.N. of Drake University, a faculty member of the Division of Nursing.

_____, has been informed about the study and in protecting the rights of the selected patient who, as well consented to participate in the study.

Any questions by the primary physician will be answered by the investigator, who will provide the completed study upon request to the physician.

Date: _____

Physician

Signature: _____

Patient Cover Letter

Date_____

Dear_____:

Bone marrow transplantation is developing as a speciality within oncology nursing. Issues a patient faces prior, during and after transplant are a priority concern to cancer nurses and are vital in the development of the speciality and in achieving optimum care for bone marrow transplant survivors. However, oncology nurses know little about what the bone marrow transplant patient truly thinks and feels.

The purpose of this study is to discover what, as a bone marrow transplant patient, you feel and think about this experience in your life. The study will recognize issues you experienced so that nursing can more effectively care for future patients.

This study is being conducted in connection with my Master's in Nursing degree at Drake University, Des Moines, Iowa, under the supervision of Sandra L. Sellers, Ph.D., R.N., Drake University.

Because you are a bone marrow transplant survivor, I would greatly appreciate your participation in this study. It will consist of six taped one-hour interviews. The interviews will consist of questions and discussion about your thoughts, perceptions and feelings regarding your transplantation experience. The location and time of these interviews will be your choice and at your convenience. Your participation is entirely voluntary and you are free at any time to stop the interviews. In no way will your participation in this study affect your care and your name will not be identified in the writings of this study. Upon completion of the study, the tapes will be destroyed.

If you would like a summary of this study, a copy may be obtained by notifying me at the address below. Again, thank you for your participation.

Sincerely,

Cheryl Blunck
1221 Pleasant #100
Des Moines, Iowa 50309

Patient Informed Consent

I, _____, consent to be interviewed by Cheryl Blunck, a graduate nursing student of Drake University. I understand that I will be asked questions about my thoughts, perceptions and feelings regarding my life before, during and after my bone marrow transplant. I understand that I will be interviewed in my home or my choice of place, a location convenient to me. I also understand that 6 one-hour interviews will be conducted plus each interview will be tape recorded and will remain confidential. I also understand that in no way will participation in this study affect my care. I have been informed that I may refuse to answer any questions or decide to terminate the interview at any point. I also understand that the study will be confidential and have no greater psychological risk than those ordinarily encountered in daily life.

I understand the results of this study will be made available to me upon request to Cheryl Blunck. I freely agree to participate in this study.

Date: _____ Patient
Signature _____

Date: _____ Researcher
Signature _____

APPENDIX B
INTERVIEW ONE

APPENDIX B

Interview One

The following interview format consist of the researcher's questions and comments in all upper case characters and the subject's answers and comments in both upper and lower case characters.

THIS IS THE FIRST OF THE SIX SCHEDULED INTERVIEWS. I THINK WE WILL START WITH WHEN YOU WERE DIAGNOSED IN 1990. THIS INTERVIEW AND THE NEXT INTERVIEW WILL FOCUS ON YOUR THOUGHTS, FEELINGS AND PERCEPTIONS BEFORE THE BMT. SO, WALK ME THROUGH YOUR DISEASE PROCESS TO THE BMT.

First symptoms were in December of 1990; June to be exact. It was just some stomach discomfort and then nothing happened for the rest of the summer until August, and I have severe heartburn; it felt like that, but it wouldn't go away and nothing would work. I went to the doctor and he didn't find anything. He said I had heartburn. I think he probably gave me Pepcid. Looking back, I did not know what that was, and that didn't clear it up. Then I became increasingly jaundiced and increasingly yellow, and all of those things. The urine was very dark and the feces were very, very black, and I was very upset because it didn't seem like things were moving fast enough. I went back to the doctor a month later and he had me go for a sonogram, and I vomited blood during the sonogram, black coffee grounds. On the basis of the sonogram, they found something but were not sure what it was. They ordered a CAT scan, and on the basis of the CAT scan they ordered (that was the same day) a couple of days, maybe a week later, I am not sure how long it was, a ERCP to see what was going on, an endoscopy. They found then what they thought was an adenocarcinoma of the duodenum and began radiation almost immediately to shrink it, because it was involving the pancreas and the duodenum and the bile ducts and the liver and everything else. They took a biopsy through the ERCP, but it was as far as we can tell incorrect. Part of it is, after I got to Iowa I found out that this particular illness probably would have killed me very quickly, had it truly been adenocarcinoma; which explains some of my doctors' attitudes because they didn't care about things like lactose intolerance and stuff, and I couldn't understand that and then I realized, they thought I was going to

die. So they didn't really worry about it. They let me go back to work about two weeks after I finished my radiation treatments, the 33 radiation treatments in conjunction with 5-FU as an inpatient and that shrunk the tumor. It took the tumor right out to the point of a year later here in Iowa they could not find it on sonogram, so it was taken care of.

We moved to Iowa because of lack of jobs and needed to make some positive changes in our life, or at least some change, so we moved. Two weeks after we moved, a lymph node appeared in my neck. I had already make contact with Buroker. His first thought, he told me later, was that the adenocarcinoma was recurring in another place and had metastasized to the bone. But he had one pulled out anyway, to take a biopsy on it, and it turned out to be T-cell lymphoma. It took them two weeks to come to that conclusion because it was not consistent with the usual diagnosis, and apparently both cancers are very rare.

So then they gradually and eventually came to the conclusion that it had been a lymphoma all along, T-cell lymphoma, and not adenocarcinoma of the duodenum. So he sent me over to see Dr. Gingrich at the University of Iowa, and his analysis that we either do a BMT now or try chemo first. So we tried the chemo first, that was my preference, because we had just moved there and to go away into the hospital would have been traumatic. So as a result, we ran six cycles CHOP/BLEO and that had an immediate effect on the tumor. Two or three days after I started the first course, the tumors in my neck disappeared and did not reoccur. So I thought a little bit about that. I finished the chemo in six months, it would have been March of 1992. I went through April and May with feeling increasingly strong and getting better, and then on Memorial Day weekend of last year I discovered a lump in my groin, and knew right away what it was, and I didn't have to guess. I called up Buroker and he said, "Well, it might be an infection or hemorrhoids or something to do with the urinary tract" and put me on antibiotics which didn't have an effect on it. So then in mid June of last year it was biopsied and found to be a lymphoma. At that point, the next step was a BMT. I went over to see Gingrich again, and they ran some tests, and looked at all the scans and everything, and found again that the only tumor was in the groin. The tumor mass was not very widespread. So then on July 28th, we began the BMT process. I had

seven or eight days of chemo, industrial strength, and had some really weird things happen with that--water blisters the last day, they were really obnoxious. I had water blisters all over my body where I know skin had been peeled off. The most unpleasant part of it was the fact that because of the toxic effect of the one drug on the bladder, that was the worst part of it I think. Then it was a matter of waiting, and a few weeks later my counts started to come up. I had visitors for the first time that month. A few days after that, one or two days, I don't know whether it was something I ate or whether it was just a reaction to the chemo, but my stomach wall started bleeding profusely. So that they were pouring back the blood into me and I was pouring them out just as quickly. And it was very frightening. That is the only time in this whole two years that I actually worried about dying. Every fifteen or twenty minutes I would go to the bathroom and there would be pure blood. I had recurrences, or two rather, recurrences of that each with decreasing severity. The third time they had me on Amicar the whole time, and then they gave me oral form instead of IV to get me ready to go home, and I had attacks of vertigo and they eventually traced it back to the Amicar and apparently the alcohol was reacting with something in my body, some drug that I had taken at some point along the way and causing vertigo. So that kept me there another three or four days until I got over the vertigo. I have had one attack of it since then a couple weeks ago while we were eating dinner out, and I had just a little sip, no more than a taste of my wife's beer, that was keeping to their recommendation not to have any alcohol for six months. But I was curious because I never had a taste for alcohol. One hour later we were walking home on the bicycle track and all of a sudden the vertigo hit me again, and whenever that happens I have to go down. I had to sit down because I could not stand up. I was violently ill, and basically Cheryl half carried me back to one of the roads, because we were between the streets. So here I am falling in the snow, throwing up violently. The only thing we can conclude is that I am still reacting to alcohol, so I won't take the chance ever of having alcohol again. So I came home from the BMT pretty weak, but not in too bad of shape. But certainly weak because I tried to climb some stairs in a store before I left Iowa City and it was just like "Whoa!". I started seeing Buroker and having my blood tested. I hated messing around with the Hickman, and I couldn't get that out fast enough, and I

couldn't stop my nocturnal feedings. I continued to recover, and then had the Hickman pulled, and that is when I passed out.

I was completely conscious, at least until I passed out. Then we had a hell of a problem because there was only the physician's assistant, then Cheryl came out of the room. Anyway, they pulled the catheter, and right as they pulled it out I got woozy and passed out. So Cheryl went running to the nurses and got nurses and Dr. Gingrich came in. I woke up and the first thing I saw was Gingrich trying to start an IV in my arm. I said, "oh, I see what you have to do around here to get to see a doctor!".

Pulling the Hickman was really a weird feeling. It was tugging to release the cartilage around it. And I just didn't like it. Even after all I had gone through, I am still woozy about some things. I would have preferred to have been sedated. I would have enjoyed it a lot more, because you then could put my feet up to get me out of the shock. Because I basically went into whatever it is called- all the blood vessels expand and everything....

ANAPHYLACTIC SHOCK IS WHAT THEY CALL IT

Yeah, and there was no blood pressure, they couldn't find anything for awhile. It was there, it was just... And they had to keep my torso up because they had to put pressure on the vein where the thing had gone into to keep from having anymore problems.

NOT QUITE THE EASY OUTPATIENT PROCEDURE THEY PREDICT IT TO BE?

No, I can hardly wait to see him next week again, and see what Karen's facial expression is when I walk in. You again!! Then it has just been a matter of recovery. Since I got rid of the Hickman, I haven't had any serious setbacks. My strength has come back gradually but steadily and my counts have started coming up, and last week when I was in to see the doctor I had 4.2 white cells and 78 platelets. You've got all that in the chart, I think. So it has just been gradual. My biggest worry right now is recurrence. I think they got it all, but I am a realist. I would probably called an optimistic realist about this.

I never ever let a doctor tell me what my chances of survival were or what my prognosis was. I am real glad, because if I had believed what they had told me about the adenocarcinoma, I might have believed them and died.

WHEN REVIEWING YOUR CHART AND THE CORRESPONDENCE FROM THE EAST COAST, I FOUND IT INTERESTING HOW MAINE WAS NOT INTERESTED IN YOUR LACTOSE INTOLERANCE. IT WAS CLEAR THEY HAD NOT EXPECTED YOU TO DO WELL AND HAD DICTATED A VERY POOR PROGNOSIS.

Yeah, because I don't think they expected me to be there at 4-5 months. I wouldn't have thought it then.

HAVE YOU READ ANY OF MAINE'S LETTERS?

I would like to. If they would just leave my chart in the room when I am waiting for Buroker, I could read those.

YOU CAN DO THAT. REMIND ME ON YOUR NEXT APPOINTMENT. THE INTERESTING LETTER IS THE THIRD LETTER DICTATED BY YOUR MAINE DOCTOR. YOU WERE DOING WELL AND HE EXPRESSED HIS AMAZEMENT YOU WERE EVEN AROUND FOR YOUR SECOND RADIATION TREATMENT. CAN YOU SHARE SOME OF YOUR FEELINGS ABOUT THIS STAGE OF YOUR DIAGNOSIS?

A month after I started my treatment and I started back to work in December. The next month was January and I did a free-lance photography shot in January which required driving for hours to do it. And the ironic part was I walked in, it was for a main hospital association and I did photography for a side show they were putting together, and I visited six or seven hospitals and did photos all over the hospitals. The PR director was showing me around the hospital, and we went down into the oncology area and low and behold, there is my radiologist standing there. He introduced me to his nurses as a walking miracle. Those were the little clues that I picked up on, because here I was expected to be on my deathbed, and I am out doing free-lance photography, on top of my regular job. So he was probable most intimately involved with my case because he is the one that read the CTs. The ERCP, the GI doctor did ERCPs regularly to replace the stint I had in my bowel duct. And then my oncologist, I wasn't terribly in love with, because he was so distant and he was just not being clear or very warm. I need someone

like Buroker to help sometimes. I don't need it very often, but there are times I need someone there to hold me.

AGAIN, BACK TO WHEN YOU WERE FIRST DIAGNOSED, CAN YOU SHARE THE EMOTIONS AND FEELINGS THROUGH THAT TIME?

I don't remember very many. I think Cheryl, my wife, could do a lot more with that. I don't remember any grief or grieving, or anything like that, which is odd, but I was real sick. I was bleeding very heavily from the tumor and involved with blood vessels in my abdomen, and so I was talking to a radiation therapist a few months later when I was in for a CT scan as a check up. And the doctor who was a radiologist was way behind. And I said, "Why is he so far behind today?" And she said, "Well, he had some emergencies." And I said, "What kind of emergency would a radiologist have?" and she said, "Well, as I recall, you were one of them, because you were bleeding so heavily."

SO, ARE YOU SAYING YOU WERE SO SICK RIGHT AT THIS PHASE OF INITIAL DIAGNOSIS THAT IT JUST DIDN'T LEAVE AN IMPACT ON YOU.

Yeah, it didn't sink in at all. I was out of it. Yeah, I was very sick and the only memory I have of that period, um, literally just about the only memory I have left is the circle of doctors standing around my bed saying it was inoperable. That is the only memory I have of that whole time, the first two weeks that I spent in the hospital. I was in the hospital for sixteen or seventeen days the first time.

AT ANY TIME DURING THIS FIRST PART, BECAUSE YOU FEEL LIKE YOU HAD SUCH A GOOD RESPONSE, DID YOU THINK THAT HELP YOU FEEL MORE POSITIVE?

I never wasn't in a positive mode. and, I guess maybe that was the depth of myself that I didn't know I had. But I never ever, like I said, the only time I thought about dying was when I was bleeding.

SO, ARE YOU SAYING YOU HAD VERY FEW CONFUSING THOUGHTS AND FEELINGS AT YOUR INITIAL DIAGNOSIS?

No, I never thought about it. I just assumed I was going to get well. That was just the attitude I had. And it is not a conscious decision, and that is why I

felt a little guilty about doubting that the transplant may not have taken, because I know that if you believe something strongly enough, it can have a major impact, whether it is true or not. So I would like to make myself believe that I am cured. But I can't just turn that off and on like a switch, is my problem.

WHAT FEELINGS CAN'T YOU TURN OFF AND ON?

Well, the things that bothers me the most, quite bluntly, is that if they hadn't got it, and it does recur, as far as I know there is very little else they can do. And that really bothers me, because I have always had options up to this point. I didn't know I needed one until I got here, but I always had the BMT in the background. I assumed they could do some stuff with radiation. I think I am just a little more paranoid than usual because my mother has been diagnosed with brain cancer just this last week. She has had lung cancer and she has multiple tumors in her brain, it has metastasized into her brain, and has started to affect her vision. So, when they called and told us that, it kind of brought things home again. Whereas, I had been pushing it away most of the time.

COMING BACK HER TO IOWA, AND THEN HAVING THE RECURRENCE, HOW DID YOU FEEL WHEN THE NEW DIAGNOSIS WAS EXPLAINED TO YOU?

Like the first time, I really felt the chemo would do it. But again, I had the same reactions I do now. There was no guarantee, and I was told that T-cell lymphoma is the hardest of the lymphomas to cure. It is one of the rarest, and it is also one of the hardest. So, I am under no illusions. With the first dose of chemo, it responded well to the chemotherapy. So, I figure if it responded so positively to the walking around chemo, the industrial strength stuff, hopefully it really did a job on it. And, you know, I had the normal reactions to the chemo with the hair loss and all that. So, my body reacted to the drugs.

YOU LOOK A LITTLE TIRED AND OUR HOUR IS UP, SO LETS STOP AT THIS POINT AND WE WILL BEGIN AT THIS POINT NEXT WEEK?

Yeah! I hope this is what you want. I didn't realize this could be so draining but I'm glad I'm doing it.

YOU ARE DOING FINE. WE'LL LEARN AS WE GO.

APPENDIX C
INTERVIEW TWO

APPENDIX C

Interview Two

AT THE END OF OUR INTERVIEW LAST WEEK, WE WERE DISCUSSING HOW YOUR INITIAL DIAGNOSIS HAS CHANGED YOUR LIFE? HOW DID YOU FEEL ABOUT YOUR LIFE THEN?

In several different ways. One is I lost my job because of the illness. I tried to do it for three months part-time, and I just couldn't function. It didn't help any that my supervisor also was messing with cancer at that time. She has since passed on. And so, she was not terribly sympathetic. Because, I seemed to be doing so much better than she was. It is not an uncommon reaction in cancer patients, I guess. One of my former employees here has cancer, liver cancer, she lives about two blocks over and I am a little reluctant to go see her because I am afraid of the same reaction. I hear she is not doing very well, and she is getting worse gradually; she has outlived the prognosis of six months. They thought she would die at Christmas time, but she is still alive. But I am afraid if I buzz in there and I am looking healthy, and the people comment on how good I look, it is the best I have looked in two years probably, because I am not pale, not too pale, and I got hair. I am just afraid that it would make her more depressed. So I have called her a few times, but I haven't gone over to see her.

So anyway, I lost my job. That was probably the biggest thing, and I enjoyed doing the job. I didn't enjoy.... Maybe I should back up, it may be helpful to back up even further. I believe the stress in a relationship with a supervisor in Maine was the open door for the cancer. I believe that very strongly, and not very many doctors agree with that, but I just really feel.... You know, Buroker said it right off the bat that this particular cancer, T-cell lymphoma, is often associated with depressed immune system and there was no other reason why I should have a depressed immune system. Because we had plenty of money, we were happily married, I had no pressures at home. Cheryl was gainfully and happily employed. It was my job, and I enjoyed the work, but I hated the relationship I had with my supervisor. And I really believe that having that go on for two years did a job on me. I am not blaming her for my cancer, I take responsibility for not getting out.

But I believe I should have left. I should have taken a lateral move and done anything to get out of that. And I know that now.

ARE YOU SAYING YOU HAVE A BELIEF THAT THIS STRESS DEPRESSED YOUR IMMUNE SYSTEM?

Yes, I was trying for promotions and didn't get them either. I came very close, and that was very frustrating. So that was kind of a precursor to the illness also. I worry now because I am in a stressful situation at my present job and I don't want a repeat. I'll talk about that later.

On another level, in terms of the change in my life, the radiation that I received has damaged my stomach, and so now I have dietary restrictions. But I am working around that. As long as I don't throw up, is really what it comes down to. As long as I can keep the food down, I can keep my weight today. But it is like a vicious cycle when I get sick because I eat too much and lose a meal that I ate, and then that hurts my stomach and I can't eat for another day or so. And I lose a couple of pounds.

HAVE YOU HAD THIS EVER SINCE THE INITIAL RADIATION?

Yes, it has gotten worse since chemo, since the transplant, because I guess there is kind of a rebound effect of some kind with chemo that causes radiation to be even worse. It has gradually gotten worse. I would like to know when it is going to stop. Because the radiologist said, originally, that I could be looking at a colostomy at some point in the future and good things like that. Of course, Buroker's reaction was, "They weren't right about the rest of that shit, so what are you worrying about?"

WELL, THAT MAY BE A PRETTY GOOD RATIONALE.

Yep, that's right. That's why I need him around.

HOW WOULD YOU DESCRIBE THE PERSON YOU WERE BEFORE THE DISEASE?

I was a lot better than I ever thought. This has done enormous things for my ego. Because, I am on an association Girl Scout executive staff, is my professional organization, and it is about 1,000 people

nationwide. And when I first became ill I received such an outpouring of letters and cards from my colleagues as well as from friends and acquaintances in the area in Portland, Maine where I was. I was on the convention steering committee, and I couldn't attend because I was in a hospital in Maine. Apparently a lot of people asked about me and they actually had to make an announcement because I was missed and the other side effect came about two weekends ago, that came out of this whole thing. Apparently my illness and the way that I have handled it has served as an inspiration to people, and I was elected to the Girl Scout Hall of Fame two weeks ago.

I am probably the youngest member and the only male in the Hall of Fame. And several people cited that reaction to how I do the job and how I function within the organization as well as how I handled it during my illness. So that has made me feel real good about myself and more conscious of stress. When I have a situation that I have to deal with at work or I have an employee who is not the most cooperative or confident person, I have to be real sure that I don't let myself get into the same kind of habits--having imaginary conversations in my head, and that kind of thing. Or I just put her in a box and try to forget when I am around her, and try to neutralize her negative effects when I am around. I have learned that about myself.

WHAT OTHER THINGS DID YOU LEARN WHEN YOU SAID YOU DIDN'T REALIZE UNTIL YOUR DISEASE, AND WHAT OTHER FEELINGS CAME ABOUT?

I guess positive attitude is one. I never thought of myself as a gung-ho always smiling person. My wife is more of a happy person than I am. I think I'm a brute sometimes. We make a good team. Certainly our relationship has been a side effect--it has gotten stronger and stronger. It has been a real difficult two years, real hard.

COULD YOU HAVE EASILY HAD NEGATIVE FEELINGS?

Yes, I could. In the hospital during the transplant, there were people who couldn't handle it, couldn't handle the stress. And Cheryl was just a trooper the whole time. She was there the entire time.

IF I WAS GOING TO SUM UP YOUR THOUGHTS AND FEELINGS DURING THIS TIME, YOU STARTED WITH A POSITIVE ATTITUDE, YOU REALIZED YOU WERE TOO SICK IN THE BEGINNING TO HAVE MUCH OF A NEGATIVE ATTITUDE BECAUSE YOU HAD LITTLE TIME FOR PROCESSING YOUR DIAGNOSIS BECAUSE YOU WERE JUST TRYING TO FEEL BETTER. OVERALL, YOU TOOK EVERYTHING IN A POSITIVE LIGHT. NOW DID YOU HAVE ANYTHING NEGATIVE DURING THAT TIME THAT YOU CAN REMEMBER?

I don't remember ever getting too down. I cry more now than I ever use to and I did then too become more emotional and I have no problem with that at all.

SO, YOU DON'T INTERRUPT CRYING AS A NEGATIVE?

No, not at all. I wrote a letter. The people who were back in New England were the ones that nominated me to the Hall of Fame. I wrote a letter to them and sent it off to the person in charge to read to the rest of the group when they meet in March. I said I cried a little bit and Penny could tell you that, Penny is the person in charge. In parentheses I put, "You know that I am always a macho man to the hilt". I am not macho at all, and don't care to be. I am not sure what led into that, I forget now.

I THINK YOU ACTED AS A VERY POSITIVE PERSON AND DEALT WITH MANY THINGS. IT SOUNDS LIKE YOU REALLY WEREN'T SURE THAT YOU HAD ALL THOSE THINGS IN YOU.

No, I really hadn't realized it before. This really made me more aware of myself and strengths and what I mean to other people. I always thought that my colleagues respected me for my work, but I found out they loved me for who I am. And that really meant a lot. I am hoping that I can accept being inducted in the Hall of Fame. I think I have to make a little speech when I get up, and I'm hoping I can stay reasonably under control while I do that. There will be 500 people in the room.

YOU WANT TO BE AS CONTROLLED AS YOU CAN?

Yeah!

NOW, LETS TALK ABOUT YOUR TIME BEFORE THE TRANSPLANT AFTER YOU MOVED TO IOWA? MOVING TO IOWA WAS A MAJOR CHANGE. WHAT TYPE OF STRESS WAS THIS FOR YOU?

I think that probably helped with the recurrence.

YOU ARE TALKING ABOUT YOUR STRESS FACTOR PHILOSOPHY?

I have been rereading Bernie Siegel which I am not a big fan of but I do use his meditation tape and that is kind of what I started doing, to meditate and I did it from the time I was diagnosed in the hospital until we moved out here. That was about the time that I stopped and I didn't meditate again until I started work again, that last month. And then I started again in mornings to try and relax. and I use guided imagery meditation, visualization, kind of things. But I find that I can't just meditate to music. My thoughts go off in too many directions, and they still go off if guided, but it is not as bad. I can concentrate every other moment on what they are saying and trying to visualize what they are saying. But Bernie is a real big believer in stress and effects of stress and the long-term, long time after the event kind of stress. So, you know, that is what I think I have going for me. There are too many correlations in my mind for it to be all coincidence. I was in excellent physical condition when I became ill. Which is one reason I think I came through it, the last two years.

YOU HAD NO MAJOR ILLNESSES UNTIL THEN?

No. I had some little stuff as a kid. I had calcification in my backbone when I was a kid, but other than that no illnesses.

WHAT FEELINGS DID YOU HAVE WHEN DECIDING TO DO THE TRANSPLANT?

Well, I never doubted that I would do it. I didn't learn enough about the transplant before I did it. So I went in kind of blind. But the first big shock came when Dr. Burns, who is a very clinical person and I use that in a sense that she is not a touchy, feeling type at all, and she sat us down at the end of a very long day of tests and said, "I think you should know that there is a fairly high mortality rate". She didn't say it quite like that, but she said that one in ten people don't walk out. We just went away kind of in shock, and we were glad a friend went over with us when we checked into the hospital, because we went out to dinner and just kind of sat and looked at each other for awhile. We had no idea that the mortality was that

high. In fact, one of the other patient's mother kept track of people, he had T-cell lymphoma and was the first person I had ever met with it, and she said that she kept track while he was in the hospital. He was in about the same time I was, a little less time, but same period. While he was in there, it was 50/50. Half the people died.

DID YOU FEEL ANY DIFFERENT ABOUT YOUR DECISION TO HAVE THE BMT AFTER DR. BURNS GAVE YOU THE NUMBERS?
DID YOU EVER DOUBT YOUR DECISION?

No, I hadn't. Yeah there was a chance I was going to die, but if I didn't have a transplant, the chances were 100% I had the most feelings, fears and doubts before I started treatment and Buroker sat us down in his office and said, "Okay, what do you want to know?" Because if I have knowledge, I am a much stronger person. So I just wanted to know what exactly was going to happen to me. I still remember you telling me one time, it was the second or third month, I said I was very nervous every time I sat down in a chemo chair, I didn't see it as a gift of God or anything like that, I saw that as a poison that they were putting in my body. I said something about being sorry about being nervous, and you said, "Hey, it's okay not to like this treatment, these drugs are not meant to be the normal body, so it's okay to be nervous or even mad."

HOW DID YOU FEEL ABOUT THE SIDE EFFECTS DURING THE CHEMOTHERAPY? WHAT SIDE EFFECTS BOTHERED YOU MOST?

Probably the hair. I have never been real self-confident in my appearance, and I elected not to wear a wig. Partly because of the cost, partly because male wigs are not all that attractive sometimes. They are not real subtle. But mostly because I wanted people to feel comfortable when talking to me about the illness. A woman I know back in Maine had a breast cancer and she elected not to wear a wig, and I admired her decision on her part. I think it is probably a little harder for women than men. Because there aren't that many bald women around. I want to make sure I clarify that. That was not a sexist remark.

I have to be careful of remarks in my life. I work for the girl scouts. And so, I wanted people to feel comfortable in asking about it. Because there is a lot of fear about it, and I don't claim to know everything,

but I know what my own philosophy is.

YOU WANT PEOPLE TO BECOME COMFORTABLE ABOUT TALKING ABOUT YOUR CANCER. DID YOU FIND PEOPLE TALKED ABOUT IT WITH YOU?

I would make it a point when I was in a new group or a new setting where people didn't know me as well to refer to it. I still do that, even with the BMT, so that people have questions. I make it clear that I have no problem talking about it or referring to it. Ironically, when my parents called this last weekend to tell us about my mother, they were dreading talking to us, because they felt we had enough on our plate as it was, and they were scared to tell us. And we actually took it much better in stride than my brother and sister-in-law did, because they hadn't been exposed to it. We are getting use to lousy phone calls and unpleasant doctors visits where we get bad news. I don't want to get too used to it. I don't want to be cynical about it or anything. We kind of expected it in some ways for various reasons.

YES, THAT IS TRUE. YOU HAVE BEEN EXPOSED TO BAD NEWS, ESPECIALLY IN THE OUTPATIENT CHEMO ROOM, AND YOU HAVE SEEN SOME OF THESE PEOPLE NOT DO WELL.

It seems like cancer has been a big part of our life since I was diagnosed. It seems like all of a sudden everybody... part of it is because we encourage people to talk about it... and so therefore, they say "Oh yeah, my aunt Matilda had little pinky cancer a few years ago." You know, I guess some of the things that I told the class that I talked to, Debbie Smith, I said I don't fight cancer, I don't battle cancer. I live my life. Cancer is part of it right now, but it is not my focus. It is just something I've got to deal with. Not a very fun thing. Now that seems like kind of a superficial view, but that is how I look at it. I am not going to worry about dying or anything else until I get there. I don't know when that is going to be. I don't want to worry about it.

WHAT AREAS COULD HAVE BEEN BETTER PREPARED FOR YOU FROM YOUR CARE IN MAINE TO IOWA CITY?

I really like the fact that my doctor here listens to me and it is almost scary sometimes, because I come in with a theory about something, a symptom, and they believe

me. and I don't feel like I should be doing the diagnosing myself. But on the other hand, I feel like I have taken a very active role in the treatment, and I know why things are happening, how they are happening, and I am just taking a pro-active role. I didn't have that option, I wasn't that active in Maine, and I don't think the doctor there would have encouraged it.

SO, YOU ARE SAYING YOU WERE NOT NEAR AS INVOLVED IN MAINE?

Yes and no. I got off on the wrong foot. I didn't have the chance to establish a relationship. You know I chose Dr. Buroker. I didn't chose my doctors in Maine. They chose me. So I essentially interviewed Buroker and asked him about his credentials the first time I met him, because I wanted to know, I wanted to make sure I got the right doctor.

I was surprised that he took new patients when I called up. He said, yeah, come in the day after tomorrow. So I was real pleased about that. So, Buroker has been up front with me. There is a down side to his optimistic nature. Is this okay to say?

YES, DEFINITELY.

I think the world of him. But he told me he was convinced that I was cured and in remission after the chemo, the first course. And, we celebrated. And then when it recurred, he told me recently that he really felt like they got it with the transplant. And I said I will have to tell you honestly, you told me once before I was cured. So I kind of have some doubts this time. Something to that effect. But I accept that as part of his optimistic nature. He is upbeat. So I have to accept the fact that he may be a little unrealistic sometimes, trying to be positive. I like the fact that he is a touchy feeling doctor. He shakes hands, hugs, and that kind of thing. So, in terms of preparation, he does a good job. The problem over the transplant, is terms of information. We never got a manual. They finally gave us the patient manual for a transplant that talked about a lot of the questions that we had or a lot of things that were going to happen. The problem was that the social worker who would have normally given us that was on vacation one or two times when we went over there. So, we never saw her. It wasn't until we were well under the transplant that we ever got in contact

with her.

ARE YOU SAYING THERE WAS ACTUALLY WAS NO INTERVIEWING PRIOR TO THE TRANSPLANT TO ASSESS YOUR MENTAL, SOCIAL OR EMOTIONAL STATUS?

There wasn't really... Gingrich was the only one... He talked to us. He had obviously talked to Buroker, and I don't know what Buroker would have told him. You know, I guess in terms of cancer patients, I now consider myself to be one the positive exceptional cancer patients, that is positive about the treatment. But I didn't ask, that was just one of the things that I wasn't very assertive about the transplant. and I think it was protective mechanism, I didn't want to know. I had to do it, and I would take what came along, but I didn't want to know in advance. Partly, because we were going on vacation for a week with my family right before the BMT. And I didn't want that hanging over my head. I think my parents know more than we did, and they didn't say much, and that was fine. We really had a good week, and had that to hang on to when it got rough.

IN REGARDS TO THE MANUAL, WOULD IT HAVE BEEN HELPFUL FOR CANCER PATIENTS TO HAVE THIS OR SOME TYPE OF INFORMATION PRIOR TO THE BMT, EVEN AT THE DR. BUROKER'S LEVEL.

I wish that I had had the book that I mentioned for the BMT because it is in lay language. It talks about a whole variety of subjects from insurance to drugs that are used. I don't think it goes into detail into drugs, but it tells about the process. It talks about the difference between auto transplant and the other. Any patients that are going over for transplant should have that book. Especially for the cost, you can't beat it. Because it basically spells out everything.

You know, the protocol is a little different from hospital to hospital, and specifically nowhere in any of those newsletters or the book, has the University of Iowa been mentioned. Which I find a little odd, and I don't know why. and I am thinking about writing to the editor and saying, "You know, I am a University of Iowa graduate here, in a sense of a transplant, and I would be happy to act as a resource, because I think they overall did a good job--\$240,000, they ought to do a good job!"

WHAT ARE YOUR FEELINGS ABOUT THE FINANCES OF A BMT?

It was \$240,000 and \$30,000 or so for the doctors. And we could be hit for probably as much as \$10,000, and it is a scary, scary thought.

YOU WOULD SAY YOUR INSURANCE HAS DONE WELL OR NOT?

We were very fortunate to have BCBS of Maine, and we had a very strong policy. We went through the teachers' union and had a big enough pool, and I would have been paying for it on my own, but it covered it. Whereas the policy that I am going on now, that I am on with my employer here, it isn't nearly as strong, this small of a group.

ARE YOU FEELING SOME STRESS ABOUT THE MONEY?

Yeah, they keep saying that we can set up payment plans and there is no interest and all this, but you know with \$10,000 even at \$100 a month or whatever we could come up with is a lifetime. The thing that has complicated things this last year is that our income went down by \$20,000, and it wasn't that much to start with, so it really has been a hit. I know that because I went to see the tax accountant today.

I'm not for sure whether to be stressed about the money because we don't have the bill yet. So until we actually have this bill that says you owe \$10,000, I don't think I will feel any stress. And even then, I am not going to worry about it. I will pay as much as we can, but I am not going to disrupt my life for that. Maybe I should, but it is just not that important. It is only money.

As long as I have my relative health, and as long as I have my wife, friends, and family, that is what is important, and their love and respect, I guess.

YOU FEEL LIKE A RICH MAN?

Yeah. I just wish we could barter that to the hospital. It is a concern, it's scary. Because this other insurance that we are going on to is going to cost more in a year, but what are going to do? But, you know, we'll get through it.

AS OUTLINED, THE FIRST TWO INTERVIEWS WERE TO ADDRESS YOUR THOUGHTS AND FEELINGS ABOUT BEFORE THE BMT. DO YOU HAVE ANY THING YOU WANT TO ADD.

Nope.

IF NOT, I HAVE EVERYTHING I NEED TODAY. WE WILL TALK
NEXT WEEK ABOUT YOUR THOUGHTS AND FEELINGS DURING THE
BMT PROCEDURE.

APPENDIX D
INTERVIEW THREE

APPENDIX D

Interview Three

OUR LAST TWO INTERVIEWS DISCUSSED YOUR THOUGHTS AND FEELINGS ABOUT YOUR EXPERIENCE BEFORE THE BMT. THIS INTERVIEW AND THE NEXT ONE WILL FOCUS ON DURING THE PROCEDURE. IF ANOTHER PATIENT TALKED TO YOU, AND ASK YOU "WHAT IS A TRANSPLANT" WHAT WOULD YOU TELL THEM?

Probably about the chemotherapy. The chemotherapy had more of an impact on my body than the actual transplant did. I didn't feel anything or experience much of anything when I received the actual transplant, per say. They pumped stem-cells into me the day after that and they pumped them in too quickly, and I had problems breathing and they put me on oxygen. There were six units and they put four units in one day and two the next. They did it more slowly the next day. But with the actual transplant, I didn't feel anything, so it was...because the day before that, or two days before that, I had my last dose of chemo. I had giant water blisters all over my body. That was more disconcerting, not really frightening and it didn't hurt, it was just really weird and uncomfortable. And I peeled like crazy, and that bugged the heck out of me because I was picking away at my skin.

CAN YOU REMEMBER WHAT DAY THAT WAS?

That would be the last day of chemo, so it would be about the seventh day of my hospital stay, and then there is a day of rest, and then the transplant was day one, so it would be day nine. But the chemotherapy, the worst thing of the whole thing for me was the urinary catheter that they put in. I hated that, absolutely hated that.

IS IT SAFE TO SAY YOU CONSIDER THE SEVEN DAYS OF CHEMOTHERAPY SEPARATE FROM THE BMT, THAT DAY ONE IN YOUR MIND STARTS WITH ACQUIRING THE STEM-CELLS?

Yes.

YOU SAID YOU HATED THE CATHETER, DID THEY EXPLAIN WHY YOU NEEDED ONE?

I needed to have it because the effects of one of the chemo drugs and I can't remember which one it is. I want to say Cisplatin, but I don't know for sure if that was it. I would have to go look at my list of drugs. They said that it had a corrosive effect on the inside of the bladder and therefore they had to flush the bladder as much as possible to keep that from happening, to drain it or whatever, so it would not sit in there. So those things were more intrusive on my life and psyche than the actual transplant or the period after that.

SO, THE INITIATION OF THE STEM-CELLS WAS A BREEZE?

It was just an IV. Most of my suffering was from the side effects from the chemotherapy, especially later on. After the transplant, it was waiting for the cells to come back, for the blood counts to come up again. Yet, I understood why they did it.

They had a chart on the wall right across from my bed, and every night would come in and put the counts down. And it remained at 0, 0, 0, 0, etc. for about ten days, and it was really frustrating after awhile to watch that and know nothing was happening.

DESCRIBE YOUR ROOM A LITTLE MORE.

Hmm. It won't take long, it wasn't very big. It was an odd-shaped room. It was not symmetrically shaped. The door was over to my right when I lay on the bed. Immediately inside the door was a hand-washing station, a sink. Right after that was a place where they could hook up oxygen and things like that, a little work station area. There was a table that kind of swings over the bed, and then there was my bed. There was the controls for the TV and lights and things, and as for where I kept my personal stuff, I tried to keep medicines and things on the table, and the console area was personal, like my clock and things like that. There was a closet. There was a long wall to the bathroom over in the corner. The bathroom contained a shower stall and a sink and place where I was suppose to do my mouth wash stuff, which I didn't do very well, and a toilet. I spent an awful lot of time on that when I was bleeding. There was a bulletin board across from my bed. Above the bulletin board was a TV and VCR which was impossible for me to reach without help. That was frustration. I couldn't even change my own movies.

Somebody had to stand up on a stool and do it for me, which may have been deliberate, I don't know, but it was certainly awkward. On the walls of the room were about 200 cards and letters, things like that. Leaning against the wall was a card about three foot by four foot that someone brought all the way from Maine.

WAS THERE A CLEAN ENTRY ROOM THAT THE STAFF ENTERED PRIOR TO COMING INTO YOURS?

No, now the more isolated...for BMT's with nonrelated marrow, I think, yeah donated marrow, had two separate rooms. There was the bubble area basically, and then there was the patient's room.

BASICALLY WHEN STAFF OR ANYONE CAME AND WENT IN TO YOUR ROOM, AND IF THEY WEREN'T GOING TO DO ANYTHING "HANDS ON" WITH YOU, THEY JUST ENTERED?

Yeah, and they usually washed their hands. Sometimes they would whip in just to push a button because it was beeping on one of the pumps. At most I had three pumps going at once, or IV. Usually they washed their hands, and those who came who didn't know they were suppose to, I pointed out to them that they were supposed to. I wasn't taking any chances.

WERE THERE OTHER RESTRICTIONS?

I couldn't leave the room until my counts reached 500 on the white blood cells. Then I could leave the room with a mask and be on the unit. At 1,000 I think I could leave the floor, and I think after that I could leave on passes. The restrictions otherwise, I had certain restrictions that weren't related to the transplant directly--dietary restrictions. I was on a liquid diet. Dr. Gingrich maintained that my bleeding started because I ate some honey-roasted peanuts that Cheryl brought in for me. That worried me for awhile. Locked myself up in here for three extra weeks because of those stupid peanuts.

DO YOU THINK THAT NOW?

I don't know what to think. I really don't know. I think, if it hadn't been that, it would have been something else, because I wasn't on a liquid diet at that point and I just started bleeding heavily and they started pumping blood in me. There were those

restrictions, the dietary kind. Other than that, I was allowed to move around, and encouraged to do so. There was an exercise bike in my room for awhile. I hardly ever used it.

WERE THERE ANY VISITATION LIMITATIONS?

No one with cold or cold sores, or anything like that. Three at a time, max. No little kids. Some friends came and they had two little ones and a ten or twelve-year old. The twelve-year-old was allowed in, but not the little ones. So there were some restrictions, but they lifted those even when.... the day that the friends came from Maine, they surprised me. They didn't tell me they were coming. Cheryl knew, the whole nursing staff knew, it was even in the computer that they were coming and I was not to be told. So those two showed up. I had a friend who had visited from the Quad Cities there. Cheryl and her mom were there, and they were all about the same time. That was also the first night that I was allowed to go of the room. My counts had come up at that point. That was the initial peak.

DID YOU FEEL ISOLATION DUE TO THE RESTRICTION?

Loneliness?

YES, LONELINESS OR ISOLATION.

I don't think so. I didn't really look forward to people visiting. The only times that I was really lonely was when I knew that Cheryl was over here in town someplace {their hometown} and not here {University Iowa Hospital} and that is when I felt lonely. It was almost as if I knew she was in Iowa City someplace, even if she wasn't in the room, I was okay. So it was real important to have that caregiver there, if just in spirit if not in body. I really wasn't lonely or bored. Time went very quickly.

FROM A PHYSICAL STANDPOINT IN DEALING WITH ISOLATION, THE MEDICAL STAFF ATTEMPTED TO NOT MAKE THIS A NEGATIVE EFFECT FOR YOU?

Yeah, I think it depends on the patient's attitude more than it does... because the nurses are in and out all the time. There is no way you can maintain modesty under those circumstances or any sense of privacy. It

was almost the opposite of loneliness, it was almost overkill in some ways. Because, there was always somebody in, and there were some times when I just wanted to be left alone.

DID YOU HAVE THE SAME NURSING STAFF MOST OF THE TIME?

Theoretically, that is the case? Theoretically, there was a primary care nurse and then assistants, or secondary, or whatever it is called. I gather that I was reasonably popular as a patient, because I had one primary and three others. And there were some nurses I never even saw because I never got a chance. But the primary was only on so many hours and there were a couple weeks she took vacation, so that didn't really have an impression on me. She wasn't there to check me out and I haven't seen her since.

WAS THERE ANYBODY DURING THE PROCESS WHO STICKS OUT IN YOUR MIND?

Certainly Dr. Gingrich does, because I looked forward to his visit every day--either to put my fears to rest or to tell him how good I was doing. One day when a friend brought a laptop computer in, I sent my report to him that morning on paper. At least I started to, he came early and I didn't get it done. But I was frantically trying to type out my status report. I guess when I wanted information and when I wanted people to be there to answer my questions. There was one time, one person, it was a nurse. She had the nighttime shift, and um, it was a night that I had had a rough time. I had blood products which kept me up most of the night, I had very severe night sweats so the sheets and my clothing were just soaking wet, and it really touched me that she came in and without any sense of bother at all, changed the sheets in the bed and allowed me to get my clothes changed, and it just really touched me that she was so confident and so positive about it. It wasn't a burden for her at all to do that and she just talked, we just talked a little, but that is when I did a lot of my talking was at three or four in the morning with the nurses. The time when I had the least amount of contact was usually around to 6-9 am. That was when the fewest came in.

DO YOU KNOW WHY THAT TIME WAS DIFFERENT?

That was because they were doing things. They were

shift changing and they were doing their reports and all those good things and breakfast was arriving and things like that, and so that is when I was left alone the most. I enjoyed certain nurses more than others, the ones that acted the most sympathetic to me. Not my biggest liking, the ones that acted kind of callous I didn't care for. I really didn't want anything to do with them. I went so far at one point to ask one of the nurses that I really liked, that if I didn't like a nurse could I request that she not be assigned. She checked with her supervisor, the head nurse, and she said all I needed to do was ask to see her and it wouldn't be any big deal. It didn't actually come to that, but I was prepared to do that. Because I said, I am not going to be here and suffer because I don't like a nurse, or a personality clash. There were two student nurses, two recent graduates that were on the floor that I had quite often, and one of them I really like. She was the one person that made me feel empowered because she had a camera and we talked about photography a lot. It is a skill that I have and was able to share with her by showing her some slides that Cheryl brought back. She brought her camera in so I could figure out how to work it for her. You have so little knowledge as a patient compared to everybody else around you, that anything that could show my knowledge was important to myself. The other graduate nurse developed almost into a, she got kind of callous about things. You know, the one was very attentive and everything, and the other one was almost trying to show maybe how battle-hard she was. But I had her for about six days straight, and I was just real tired of her.

DO YOU THINK THAT HAD SOME BEARING ON HOW GOOD OR BAD THE SIX WEEKS CAN BE?

Yeah, and in my case it was nine weeks, so it was... You know, I looked forward to see who I was going to get that night. Because that is really when I had a lot of contact, because Cheryl was there during the day, and she would usually leave about 9:00 p.m. so I would be on my own after that.

DID YOU FEEL A SENSE OF COMFORT AND CONTROL WHEN YOU ADDRESSED THE ISSUE OF THE NURSE THAT BOTHERED YOU, EVEN THOUGH YOU DIDN'T HAVE TO REQUEST THE CHANGE.

Yeah, you know, it helped. I didn't want to do it, because I didn't really want to cause waves. But on the

other hand, I didn't want to be unhappy and I know my own self well enough that I would have stew about it if I didn't do something about it. Again, I have learned the value of taking control. Things that I can.

WHAT STEPS OF THE PROCEDURE OR HOSPITALIZATION, DO YOU THINK COULD HAVE BEEN DONE TO MAKE YOU FEEL MORE IN CONTROL?

We have talked about some of it. We talked about, I think, the information that was provided and when. I think that was just an anomaly of the system, it was not standard procedure. For me, knowledge is most important of almost anything. And so, the more I know in most cases, the better off I am. I don't want to know the odds or statistics, I want to know actually what is going to happen and leave it at that.

DO YOU FEEL LIKE YOU WERE GIVEN THE INFORMATION AND EXPLANATIONS AS YOU WERE GOING THROUGH THE PROCESS?

Yeah, I was amazed with the amount of information I got in the eight weeks from the nurses because they were not at all reluctant to tell me what was going on. If I didn't think what they told me was right, I would ask the doctor. But I didn't always think that what the doctor was saying was right either, so... Part of that was perceived knowledge of the doctors, part of it, I perceive Dr. Gingrich as being much more knowledgeable than Dr. Lee. Gingrich has been at it for ten years and Lee hadn't. And so some of the things that Lee said, some of the things, there are some things that I can sense about myself, about when I was on the Amicar, it was to try and stop the bleeding, and they put me on some oral dose instead of IV. It had alcohol in it and that caused vertigo. And they first tried to figure out that it was something else, and they finally came to the conclusion that it was that medication, and that was what I had suggested in the very beginning. He said, "Well, I think you are right Gordon!" I said, "Thank you very much." I was going to say, "Are we paying you the big bucks for what?" So, I don't know. I guess I lost track of the question.

I WAS ASKING IF THERE WAS ANYTHING THAT COULD HAVE BEEN DONE DIFFERENTLY.

Oh, yeah. Really just the initial information, but I don't know what else since then. Nothing comes to mind

right off the bat.

YOU HAVE TOUCHED A LITTLE ON THE SIDE EFFECTS YOU FELT FROM THE CHEMOTHERAPY IN OUR FIRST INTERVIEW, THE BLISTERS. CAN YOU DESCRIBE ANY OTHER SIDE EFFECTS YOU FELT?

There weren't really that many comparatively. I didn't have mouth sores. I had mouth sores one day, and it was a blood blister that developed almost during the course of the day from nothing to a real significant thing that I could feel. And then it went away. And so I had virtually no problems with my mouth, much to the amazement of the doctors and nurses. When they administered the chemo, I really didn't feel much else. You know, I felt lousy but I didn't really... I don't remember having any physical symptoms. Blood blisters, the urinary catheter, those are the two things that I remember most from that period.

NAUSEA OR VOMITING WAS NOT A PROBLEM?

There was some. I have a suspicion that in my case with chemo, nausea and vomiting are as much from nerves and mental things, pressures, as they are from actual physical manifestations. I think there probably was some, but I experienced that throughout the whole disease, and I am so used to it by now that I don't even think about it.

WHEN READING THE LITERATURE, SOME PATIENTS TALKED ABOUT HAVING SOME DELIRIUM, FEELING CONFUSED. DID YOU EXPERIENCE ANY OF THESE EPISODES?

No. I may have been out of it, because they drugged me with Ativan and Morphine during part of that period. Not so much before, but after, because I had pain where I had the incision. There was a thrombosis, a little blood clot there, and it hurt like heck. I also had back pain that was associated with the spine. Maybe it was side pain, I can't remember. Where is the spleen?

YOU WOULD FEEL AN ENLARGED SPLEEN FROM THIS SIDE. WHY DO YOU MENTION YOUR SPLEEN?

Because the spleen filtered out something, I forgot what it was.

YOUR PLATELETS.

The platelets. That's what it was. They felt the administration of platelets was doing a job on me. So I had Morphine at various points. I did get real attached to Morphine. I think that was kind of nice and Codeine for diarrhea to slow it down. So, I was drugged to have pain control, but not delirious.

YOU MENTIONED EARLIER THAT THE ONLY TIME YOU WORRIED ABOUT DEATH WAS WHEN YOU WERE BLEEDING AFTER THE TRANSPLANT. WHEN DID YOU WORRY ABOUT WHETHER THE BMT WAS GOING TO BE A SUCCESS OR NOT?

I almost have a sense of guilt about that because I feel like I ought to assume it is going to be successful, to maintain a positive attitude. But the realistic side of me says that I don't know that, nobody knows that and for me to say that yes it has definitely been successful isn't true. And it probably is. I am beginning to believe that, but I don't know that for a fact, and so... I think it really didn't cross my mind very much. I know that I didn't... if I thought, "If I'm going through all this it darn well better be", you know spending all this time and money.

DO YOU FEEL A SENSE OF SUCCESS THE FARTHER OUT YOU ARE FROM TREATMENT?

I feel better and better about it. I don't know about success because I can't identify how much of a contribution I actually made to the process. I think I had a contribution, but I don't know how much it is or what it was. I am just trying to keep a positive attitude. I think that is... you know, I try to be upbeat and not feel sorry for myself, but some of the drugs made me very emotional, I think. The process made me very emotional, and there were times when I was just really on the verge of tears. I had the doctor tell me once not to get all emotional about it.

HOW DID YOU FEEL ABOUT HIM TELLING YOU THAT?

I didn't like it. It was my right to be emotional, and maybe it embarrassed him and I am sorry if it did, but that is not his problem, it's my problem. It wasn't his place, I don't think, to tell me... You know, because I feel like, what's it hurt if I can get it out of my system or feel better for it, or even if I feel a need, who is it hurting? I don't think anybody, in my opinion.

AFTER THE PHYSICIAN'S COMMENT ABOUT CRYING, DID YOU EVER TRY TO STIFLE THAT FEELING?

No. And I cried a great deal when I first came home, but again, I think a good part of that was the Ativan. It is a downer I think, isn't it?

YES, IT CAN BE. IT IS ACTUALLY AN ANTIANXIETY MEDICATION.

I don't react within norms usually with drugs. It takes a lot of anesthesia to put me under sedation. It takes me a long time to come out of it, and so I suspect that I reacted a little bit out of the ordinary to the Ativan too.

WOULD YOU SAY YOU HAD DISTINGUISHABLE "GOOD DAYS" "BAD DAYS"?

Umm Hmm, definitely. I would basically start up my conversation with Dr. Gingrich in the morning as feeling good or bad, compared to the day before. Or just feeling good about it, period. He would come in, and I would always make it a point to tell him exactly how I felt. If I felt lousy, I would say, "I feel pretty lousy today. I feel rundown, I didn't sleep well last night." Usually my good days and my bad days were tied almost directly to the amount of sleep and the continuity of my sleep the night before. If I got a lot of blood products that interrupted my sleep every hour, I usually felt pretty poorly the next morning. I was very, very groggy in the morning. I would discourage them giving me anything other than Ativan at night, and it was probably enough. But they tried Demerol and a couple of other things to help me sleep. I felt so horrible in the morning, that I didn't want to get going until about 10:00, and for me that is real late. And I still have some of that left.

HANGOVER FEELING?

Yes. I'm still not a morning person like I used to be. I would think nothing of getting up at 4:00 or 5:00 a.m. and going to work sometimes at 5:30 or 6:00 in the morning. Some of that probably was workaholic symptoms, and some of it was just wanting the quiet time.

WHAT WAS THE PERCENTAGE BETWEEN GOOD AND BAD DAYS?

Probably more bad than good. There were some days that I just felt like I could conquer the world, you know, even in the hospital. I would say maybe 2/3 to 1/3 bad/good. There were more days that I felt down or physically lousy than the good days.

DO YOU THINK YOUR BLEEDING COMPLICATION CREATED MORE BAD DAYS?

Yes. Definitely. Because it was... I wish I had kept the charts in some ways that showed the progress of my counts. I left them up on the wall when I left the room. That seemed to be the right thing to do at that time. I know it was at least ten days with zero counts, and I know it was probably another week after that... It seems to me that it was around mid-July, no mid-August, before I could even think about leaving my room, which meant my counts were up. But then the last three or four weeks were down again because of the bleeding. So, you know, there was a period when I felt really good, and they were even worried out in the unit that I was walking too fast, because I was just pulling my little pump around on wheels and they said, "You know if you fall down, you are going to be in big trouble because you don't have any platelets, and you are going to bruise like crazy and bleed." But I felt perfectly coordinated and perfectly capable and I wanted to push myself to see how much I could do. Then the bleeding started, and that discouraged me from going out. Then I lost a lot of my courage at that point. It was compounded by the fact that I had the dizziness from the Amicar, the vertigo and vomiting. You know, I didn't trust myself to stand up any more and so the first time that I went out with Cheryl to go shopping was on a pass. It was while I was still experiencing vertigo, and so I basically held on to something the entire time I was out of my bed and I was exhausted after a couple of hours.

MENTAL STRESS AT THIS TIME?

Yes. But being dressed and just being around people... I sat while she shopped. At the end we saw a little wheelchair cart that they have that would have been just perfect because I could have gone with her. But as it was, I just sat and watched people.

YOU MENTIONED THE STRESS FACTOR EARLIER, WHAT MORE CAN YOU TELL ME ABOUT THIS?

Again, I am trying to take control of a situation so I talked to my boss about it a little bit. She gave me some tapes on how to deal with difficult people and leadership secrets of Attila the Hun, so that I can learn some techniques to deal with a difficult person in my life. Also there is a workshop scheduled by DMACC that I am thinking about taking. It is the same topic.

SO YOU HAVE CONFRONTED THIS STRESS. HOW DO YOU FEEL ABOUT THAT AND DO YOU FEEL MORE IN CONTROL OF THIS SITUATION?

This time was kind of a drop. I wanted to cut... I feel like we are overspending on the budget in a certain area, and she doesn't. She wants to keep spending it. So she voluntarily cut other things out of her budget instead of that. So the budget was cut, and we came up with two or three thousand dollars that we could do without this year, but I kept the issue alive by saying that we were going to have to cut in this area.

So like, I'm not overwhelmingly happy at my work. I would like to be. I would like to look forward to going in to work every day and really enjoy it. Not to the exclusion of all the rest of my life and other activities. But I really would like to do something where I didn't have long-term stress. Right now I feel pretty well trapped because, until my health stabilized and I can show a track record of being healthy again, then there are not going to be very many employers that would want to hire me. So I really don't have very many employment options. And, you know, the two of us don't have very many employment options or survival options if I lost my job or left. Then you have to balance that again, and say well, is it affecting my health? And that is more important than anything else. But if we are living on starvation rations, that is not healthy either and that is a different kind of stress. And I just feel like I could be trading one for another. So, I don't know what to do about it except to try to maintain a coping mechanism to put in place. But, geez, yesterday I had pressure from above to get budget numbers done and I had unpleasantness from below because she didn't want to mess with her budget and do without. And I really felt between a rock and a hard place.

IS IT POSSIBLE YOU HAVE BEEN PUT IN A POSITION TO BE RESPONSIBLE WITHOUT THE AUTHORITY?

Yeah, authority is not there.

THAT DEFINITELY IS A CONFLICT.

It is. The executive director has a pretty firm hand over everything. She knows a lot about what goes on, and... You know, I have responsibility but I don't have a lot of authority to change things dramatically. So, we work with it.

IN ORDER TO HAVE THE AUTHORITY, YOU MAY HAVE TO CLIMB THE LADDER WHICH CAN CREATE NEW STRESSES. DO YOU THINK THAT MAYBE HAVING CONTROL WOULD ALLEVIATE THIS OLD STRESS?

Yeah, but there are new stresses, and you gain control in some directions and lose it in others. The higher you go, the more vulnerable you are. Especially in my organization, where the higher I go, if I go to the top position, I have 24 volunteer supervisors, or whatever the number is on the board of directors. And to have 24 bosses is not terribly endearing to me. One thing... I had lunch with a friend of mine who I was talking to about a situation, and she said that she felt that I was trying too hard too fast. That I ought to give myself some time and try and ease back into things a little more slower than I have. I have noticed that in myself, but I feel almost an internal pressure to prove that I am back and functioning. I had been more aggressive and less caring because of that, and so I have been trying to watch myself. But case in point, as we are working with a consultant for fund development and we are paying them some pretty big bucks to do some things for us. It has been on the average of about \$10,000 a month, and it is a good business to be in, obviously. And so, there is this situation that needs resolution, but I am not sure exactly where the problem is, whether it is with them or us. It could be either way. I am beginning to sense that it may be more with us than them if they are ready to produce but we are holding them up because we are not doing some things, some of our volunteers are not doing the things that they said they would do. So, I don't know.

DO YOU THINK THE PERSON YOU HAD LUNCH WITH HAS A POINT?

I think it is me. I want to do the very best job. I can and I always have. And I don't know how to accept... I don't know as well as I could probably how

to accept less than my very best. It may be the best that I could do at the time, and I have to learn to accept that.

DO YOU FEEL YOU NEED TO PUT THIS SAME POINT TO YOU PHYSICAL AND MENTAL RECOVERY?

Yeah, I think so. You know, I am finding as my body gradually goes back to normal... You asked me about pain. It was more like selective forgetting. I experienced very severe cramping when I first was bleeding that often was associated with the increased bleeding, and it just hurt like hell. You know, I would double over and there was nothing I could do to relieve the pain.

They were putting fluid into me and I ballooned up to 150 pounds and about 30 percent of that was water. So my body still.... I don't know what normal is. I told the nurses "I don't know, it's not my body anymore. It is not the same one I grew up with." And so I have to make those adjustments now, and understand that what is right, what is normal, and what is not.

DO YOU HAVE GOALS?

Well, yeah. In a way I guess. I know I can't push my body yet as hard as I would like to. I have decided that when I get back up to 115 pounds which is five pounds gained, then I am going to start doing some of my work outs.

FIVE MORE POUNDS?

A total of five from the starting point of 110. When I get to 115.. I don't want it to go to all fat, and I am afraid that if I take on ten pounds, it is all going to be fat and it is not going to be anything else. So, I am thinking about renewing some of my... like, just a real light work out. Just the fact that I have it, so when I am able to do it full speed, I can. That will be kind of one of my goals. I used to be in the habit of every morning, no matter what, I would get up and exercise and I am out of that habit now. It is horrible.

It almost became an obsession. It was that important to me to work out, and even on weekends when I had time, I would see how hard I could push myself for an hour on

the exercise bike. and I think my top was maintaining something like... I did 40 miles in an hour. Now those are not road miles, those are exercise bike miles and there is a difference. But it meant the revolutions that I was doing was like 100 rpm per minute for a full sixty minutes. You know, I was really in good shape.

DO YOU FEEL LIKE YOU EVER USED EXERCISE AS A STRESS REDUCER?

Yeah, no. It supposedly was suppose to have helped, but I don't think in my case it really did, because again, I was not controlling my thoughts and my conversations in my head and that kind of stuff.

I AM IMPRESSED WITH YOUR ABILITY TO ACTUALLY CHANGE YOUR MENTAL THOUGHTS...

I think I have a lot of self discipline, if I put my mind to it. I believe that.

WE HAVE DEFINITELY GONE OVER OUR TIME LIMIT. YOU HAVE ANSWERED MY QUESTIONS REGARDING DURING THE BMT. YOU EXPRESSED NOT BEING ABLE TO REMEMBER EVERYTHING THAT HAPPENED DURING THE PROCEDURE BECAUSE OF BEING SO SICK. CAN YOU THINK OF ANYTHING ELSE YOU WOULD LIKE TO TELL ME?

No, not really. Like I said I don't think I remember a lot of things that happened during this time. Cheryl could probably fill in the gaps. Maybe you should do an interview with her at the end.

YOU MIGHT HAVE A POINT, EVEN THOUGH MY STUDY CONCERNS YOUR THOUGHTS AND FEELINGS, I COULD VISIT WITH CHERYL AND SEE IF THERE ARE ANY GAPS. OTHERWISE I HAD PLANNED ON TALKING ON THIS AREA AGAIN NEXT WEEK, HOWEVER, SINCE WE TOOK LONGER TODAY WE ANSWERED THE REMAINDER OF MY QUESTIONS. NEXT WEEK WE WILL THEN TALK ABOUT YOUR THOUGHTS, FEELINGS AND PERCEPTIONS AFTER THE BMT.

APPENDIX E
INTERVIEW FOUR

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I REALIZE IT MAY BE DIFFICULT TO CONCENTRATE ON OUR INTERVIEW TODAY. SO LETS TALK ABOUT WAS HAS HAPPENED THIS PAST WEEK INVOLVING YOUR QUESTION OF RECURRENCE.

What I was referring to was the idea of recurrence. It would be my third recurrence after the original illness, if this indeed is one. I thought, just bleak as possible, thoughts. Because everything that I had heard was that the transplant was the nuclear bomb as Buroker put it at one time and that it was much more of a high risk but was also a high success ration kind of thing. I really believed the doctors in Iowa City when they said that they thought that I was cured of cancer and I don't always let myself do that, because it is taking a risk that if they were wrong, I was laying my emotions open to injury, I guess. So it was really kind of devastating when I found the lymph node the other night. I just broke into a cold sweat. I was just really upset and I lay there for awhile trying to determine if I was imagining it or if it was really there. Then I went and got Cheryl and turned the TV off and asked if she could talk to me. But all that night I lay there... Buroker knows me pretty well, He said, "You really do A LOT better when you know what is going on." And that is true. If I know what the situation is, I can mentally deal with it. It is the unknown that scares the heck out of me. All that night I thought about what my life span would be, I actually thought about death. Because always before there has been another option, there had always been something left and I didn't think there was this time. I didn't think I had any options and I thought... You know, I didn't think I had any options, and I didn't know what treatment, if any, was available. It was real scary to me. So it helped a lot just talking to Buroker, even though nothing conclusive came out of the session with him. Just knowing that all was not necessarily lost was very helpful to me. I still don't know what the options are, if it is lymphoma. I am glad that he wasn't impressed with the CT scans today.

CAN YOU ELABORATE, OR DO YOU FEEL LIKE ELABORATING ABOUT ANY THOUGHTS OR FEELINGS YOU HAD WAITING DURING THE NIGHT BEFORE
YOU CALLED THE PHYSICIAN THE NEXT MORNING?

I really thought in terms of... almost practical terms. Would I be able to go to my conference? Would this affect my trip to Florida? Would this affect my trip to St. Louis at the end of the month? Would this affect our vacation going out to see our friends? You know, I thought in terms of the things I am looking forward to and what it might do.

Ultimately, the farthest I can see ahead right now is October and the Hall of Fame. You know, I remember thinking that it was good that I am technically elected to the Hall and I will be inducted whether I am alive or dead. I actually didn't know what my life span would be if there was no treatment available for me. Would I make it to October? Those are the kinds of things that went through my head again and again. I wasn't reading a real upbeat book, so that didn't help. I can handle serious books if I am not down; but if I am down or upset, I need a James Harriet book or something like that, that is upbeat and warm and fuzzy. So, I quit reading what I was reading and started reading a Harriet book that I have. I have read them many, many times, but I can't find enough of them enough of that kind of book. So I was pretty down when I went into the office. I wasn't moving very fast and I was just upset and depressed until I could get a hold of Pat and say, "When can I see Mr. Buroker?" Very considerately, she put me at the head of the list to come in.

WHAT WERE YOU THINKING WHEN YOU CAME INTO THE OFFICE THE NEXT DAY?

The office represents treatment, warmth, and love, because we know you and Pat and Michelle pretty well, and Buroker, and the people at the front desk, and it was just like coming to family, I felt. Just the warmth of the place makes a difference to me. I have never had any really painful episodes there, probably the bone marrow biopsy was the biggest pain in the butt that I had. But, the chemo was terribly intrusive. I handled it well. I hope I don't have to go through chemo again, but if that is one on the options I elect to have my hair. But I don't have any negative vibes in that office. I have more probably with the University of Iowa than I do in the office here. When we got the worst news, probably the biggest blow that we got when we found the lymph node in my groin last June, was lymphoma again, and then a bone marrow transplant. Buroker called me at my office and told me, and I called

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Cheryl here and told her, so we weren't even present physically in the office when it happened. So no, yesterday didn't bother me coming in because it represented help.

I REMEMBER THE DAY, AND THE STAFF TENDS TO GET VERY INVOLVED WITH THEIR "FAVORITE PATIENTS", KNOWING THIS, DID THIS BOTHER YOU ANY WHEN CHECKING IN?

No, because I don't detect it from the front office people. I'll tell you a story about the front office people if you turn this thing off. But Michelle and Pat, you know Pat gave my hand a little shake when I went by, no... I didn't feel... You know, I felt concerned interest at that point. You know, I have been there so often that most of the rest of the staff knows me.

EVERYONE WAS VERY CONCERNED AND WORRIED ABOUT YOU PLUS YOUR ANXIETY WAS VERY EVIDENT. WE WILL SHUT OFF THE TAPE SO YOU CAN SHARE YOUR OFFICE COMMENT WITH ME.

NOW, IF YOU CAN PLEASE SHARE YOUR FEELINGS AND THOUGHTS ABOUT THE REST OF THE DAY YOU CAME TO HAVE YOUR NODES CHECKED AND WHAT YOU WERE GOING THROUGH WAITING TO FIND OUT THE BIOPSY RESULTS.

At first, I withdrew. But you know I was laughing by lunchtime. It was that dramatic a turnaround. I slept better last night. I still use Sominex or Nytol or one of those things to try and sleep through the night and last weekend I went two nights without it and did fine. I don't know what the difference is and I am not even sure the stuff works. Whether it could be some sort of placebo effect where I think, "Well, I took this sleeping pill, therefore I shall sleep through the night", and I do. We were at a friend's house last weekend, so it wasn't the normal home. Sleep was better last night. Still, it took me a long time to go to sleep. I wasn't tired and I still am not moving too fast.

WHAT WAS TODAY LIKE?

It is weird. I am not worried, and I don't know why. I should be. I have dropped into my "Whatever happens we will take care of it" mode.

TALK ABOUT THIS MODE?

I dropped into this mode sometime yesterday afternoon. As long as I know there is something that can be done, you know, when I reach the end of my rope that is when I am going to get really scared. When there is nothing else. My worst fear today for those scans was finding that there were enlarged lymph nodes in my abdominal area because I cannot have any more radiation. I have had the limit. So I was scared until we saw the scans. You know, Buroker said the lymph node under my arm could be radiated. I know that the body... there is a tolerance level for the entire body that may be concentrated in one area, but I would rather have a little more radiation and take my chances than die from lymphoma. I understand that if I get radiation to that spot... I asked him yesterday, isn't lymphoma... I used the term systemic, I am not sure if that is the right term...

But my point is, it is in the lymph system, and therefore if it is in the system in one place, it very likely could be in the system some place else.

Any radiating... that is why I wondered at the University of Iowa, why they gave radiation to a lot of patients to their tumors, because that is just kind of a stop-gap effect, it is not a cure-all, it is not a killer. But in my case, if I have lymphoma again and there are no other options, I will take the radiation if it will extend my life some.

I had radiation, as you know, to the large tumor in my abdomen and it shrunk it down to nothing, to the point where they can't even find it now. So... there is not even hardly any scar tissue left from what I understand. So... if the illness is back and it is not an infection, at least... you know, just keep me going for awhile. One of the encouraging things that Buroker said was that he has been treating a patient for ten years with lymphoma. I don't know exactly what that means, whether that is a person who had lymphoma ten years ago and is now in remission and is seeing him on an annual basis, or if that means that the guy is actually survived lymphoma with various treatments over the past ten years. But it was encouraging, whatever the case.

IF THEY SAY CHEMOTHERAPY, THE HAIR CONCERN, WHAT ARE YOU SAYING?

I would be real discouraged. I really thought that I

was done with chemo. If I had to lose my hair again.... I guess my question would be-- is the chemotherapy... the chemotherapy is not going to knock the cancer out probably... if it didn't get knocked out by the transplant, you know, what could we do here that would be any more stronger, unless there is a new drug or some other treatment on the market that was not available. So, if I have to go through chemo, especially if I'm going to lose my hair, I want to make sure that it is going to do something worthwhile. Last time I went through chemo for six months, and the cancer recurred within three months.

RECURRED THREE MONTHS AFTER YOU COMPLETED TREATMENT?

Yeah, ironically the day I discovered this was one year to the day of my last treatment here. So you know, it recurred on Memorial Day, so I had all of March, all of April, and most of May and then it came back. So, if the chemo will help keep it at bay, then good. But if it isn't going to make a sniff of a difference than I would say no. That is... you know, I would opt for the radiation of being least intrusive on my life probably. Especially if it is up around the arm where the scar tissue would have a minimal effect.

SO WHAT TYPE OF SELF-TALK ARE YOU HAVING TO DO?

Well, you have to understand that I don't always do self-talk. I try to prevent self-talk. That's where the key is in stress management for me. And I just try not to have conversations in my head unless they are positive ones, which is I guess a form of what athletes do when they visualize, use visualization, to run their race in advance. I just stop myself from thinking. I had thought that... you know, it is easy to say with conversations, but the other night when I was lying on the bed all night, it wasn't very easy to stop thinking about it. I would stop on one subject and get started on another one. I tried reading, but again I didn't have the right book to distract me. So, I was glad Cheryl was there, Cheryl the wife.

ANYTHING ELSE YOU WANT TO TALK ABOUT AS FAR AS ABOUT TODAY OR HOW YOU ARE FEELING NOW?

Well, like I say, I am not really dwelling on it. I take the Tylenol so that the pain is reduced so that I don't get reminded of it when I move my arm. I am

favoring that arm to keep from moving it.

TENDER?

Yeah. Certain movements.... if I stretch it particularly.. go over my head. It was uncomfortable lying on the CT table today, because I had to put my arms back over my head. You know, it is not really, really, really sore, but it is enough to remind me of it. and I am just saving myself the mental anxiety, you know... if I ignore it, it will go away kind of thing.

I UNDERSTAND YOU ARE GOING TO BE GONE FOR A WEEK TO GO SEE YOUR MOTHER, HOW DO YOU FEEL YOU'LL CONTROL YOUR STRESS?

There will be other things to focus on. That was one of the nicer aspects yesterday, was how sympathetic everybody was...because I guess, I gathered Buroker went right out of the treatment room and told Pat and Michelle about my mom and I told my parents last night about the lymph nodes. I am not any good at lying and they asked me directly how I was doing. And I could have just flat out lied and said, "whatever". I was more upbeat with them than I felt. But they had just gone through an MRI because they suspect the spine is involved. And so they were very tired and very depressed. I told them... I didn't make it into anything, any big deal, and I am going to call them tonight and say that we know that the scans look okay at this point. The fact that the lymph node doesn't even show up on the scan. Do lymph nodes have different consistencies, like a cancerous lymph node vs. the infected lymph node.

YES, BUT YOURS HAS BEEN A LITTLE UNCOMMON FROM THE TYPICAL. USUALLY INFECTED NODES ARE TENDER, MORE FIRM AND SOMETIMES VERY HARD. HOWEVER, YOU HAD ATYPICAL SYMPTOMS THE FIRST TIME AROUND, SO ...

This is definitely uncomfortable, but so were the ones in my neck.

ANYTHING ELSE?

No, lets get started.

WE HAVE DEALT WITH THE PAST, TALKED ABOUT THE PROCEDURE ITSELF, SO NOW LETS EXPLORE YOUR EXPERIENCE AFTER THE BMT.

Well, to back up one step, I had to come back in about a week after I left the hospital, after I was discharged. And they wanted me to come back the following week. And I said, all you are going to do is to poke me and prod me and take my blood, and I can do that very nicely thank you in Des Moines, and I don't need to drive five hours for that. And they agreed. So I went to Buroker instead and they tested my blood. The nurse was coming in for the nutrition, night time nutrition stopped, so she drew my blood once or twice. So I didn't need to go over to Iowa City as frequently as they would have asked me to do if I hadn't stood up on my hind legs and said I don't need to do this. Let's be real about this. Then I had to come back in November, which would have been maybe three months. Yes, it was a three-month checkup after transplant. Close to, I don't know. Anyway, I had to come back in November and they did a CT and they did pulmonary, and they did a chest x-ray, and blood and everything was okay. There was some reduction in pulmonary function but not significant. So it would be a good excuse if I got out of breath on my exercise bike. Then I went back in February for a six-month checkup. Oh, they also pulled my Hickman and then in February I went back and all they did was a CT. So now I don't have to go back for six months. They were pleased enough with the situation that they felt six months was reasonable, so it would be like a one-year anniversary basically.

WHAT TYPE OF FOLLOWUP AFTER THAT?

Probably annually.

We were talking today, this is almost off the subject but not quite, we were discussing positive thinking and I have a lot of people in my office... My office has not been the most congenial one to break into. They are very hard on their people. In fact, a bunch of them, we went to this funeral last week, I rode up with three other people who had been there a long time. And they all agreed that it is a .. they are a hard crowd to break into. They are very standoffish to new people. And I said, "Why?" I found that the crusty New Englanders were more accepting than my coworkers in the friendly Midwest and they said they didn't know why,

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they just didn't. You know, it is just kind of an initiation for new people. So, it has been nice that this latest little crisis this week, I have gotten a lot of support from people which I hadn't before and I feel like I have finally started to fit into the group, and it has been a year and a half. It just seems like an extraordinary amount of time for me to take to do that. Because I get along with people well. I do a good job.

HOW DID YOU GET THIS STANDOFFISH GROUP TO EVEN BRING THIS UP?

I don't think I did because I made a fuss about it at first. I said, you know, half the group isn't talking to me, or obviously is hostile. It didn't help that I am good buddies with the executive director. I am not going to give that up, that is also one of my mainstays. But, that closeness hurts me and I accept that as a part of the game, but I don't go squealing on everybody and they have no reason to say that I do, so they can't hold that against me. I am not sure how it came up. It was in the car coming back from the funeral, and somebody... who all was in that car... there is one woman on the staff who has spoken maybe two dozen words to me. So I started getting that output when I was less tolerant, and I came back, and I started making comments to other people that, "Well, you know, people around here have been real friendly with one possible exception." I didn't tell very many people a name, but they figured it out. So this woman comes prancing into my office, you can imagine this is a way-overweight woman, prancing is not a good word! She comes into my office, big smile, and says "Rumor going around that I don't talk to you, and we are too small an office for something like that to go on." and I said, "Well, you don't," and she said, "Well, its not that I don't talk to you or want to talk to you, its just my personality," and I said, "There have been times when I have said 'Good Morning' to you and you have grunted at me, and I am sorry but that is rude, that is just... I don't want long conversations, I just want some courtesy... common office courtesy." So she denied all knowledge of this and she was sitting in the back seat with me on the way up to this funeral. But anyway, it came up in that conversation and I don't know why or how, but it did.

QUITE A BREAKTHROUGH.

Yeah, that they included me in the conversation.

AND THEY ADMITTED...

The one who admitted it, particularly, she is a Black woman who I think is somewhat distrustful. It is kind of a discrimination, not a conscious one. But she keeps her space and her distance. I can just tell... I do it just to probe every once in awhile. I will say something when we are working together on a project as we have been... I say, "We make a good team." And she just backs right off. You know, the wall comes up. You can just see it and hear it in her voice. I watch for it now because she is normally very friendly as long as I don't intrude on her space. But we have gone too far from this conversation.

THAT IS OKAY, THIS IS PART OF IT. SHARING YOUR THOUGHTS AND FEELINGS.

I have felt a lot more support from the people this last week. Because I went in kind of with the thought of being the strong, silent type and not telling people, but I just couldn't. I need that support. So I told one person and then I told another person and it got around the office after that, because I knew it would, and it was okay. So people have been real interested to know how things are going. I have always been very open about discussing it, as you know, and what I am going through. In fact, we had a phone call last night from a guy that I haven't seen for fifteen years, give or take. He and I worked together, he and his wife and I worked together in northern Maine at the boy scout base back in the middle 70s and we have kept up our correspondence over the years but we haven't seen each other or even talked on the phone since then. He called up last night because his wife has an aunt who has bone cancer and some blood disorder, or I don't know what, but she wasn't sure. She knew it was bone cancer and she wanted to know about transplants, as we have been sending our little newsletters out to everybody. Her aunt got all excited and mentioned to a doctor, she is 60 and her doctor said something about her age. Debbie told me this after, well if she is 60 she won't be a candidate for transplant. They only do people in their 30s and 40s mostly, because it is such a big amount of money, that they don't want to invest in older people that are not going to benefit from it for very long. But you know, I have become kind of a local authority on that for some of my friends, I guess because I sound like I know what I am talking about. I just say whatever

Buroker has told me.

THAT IS BECAUSE YOU ARE A SURVIVOR.

I guess so. That is what got this whole conversation started was the positive attitude, at lunch today in the office, we were talking and they said, "Well, think positively about whatever this is that is wrong" and I said, "Where do you draw a line between optimism and realism?" I would like to be optimistic, but I know from real life that...

The analogy that I used before was that when you cut off someone's head, I don't care how much positive thinking you do. It is not going to make it all better. You know, there is a point where positive thinking just won't cut it. I don't honestly believe that if I think real positively about this thing in my arm, that if it is lymphoma, I am going to turn it into infection. I just don't believe that. I am sorry, I don't. It is either lymphoma or infection or whatever it is. All I can do I think is just think positively about it and handle it. I am not going to waste time trying to think it into something that is is not. So, you know, I think I am a fairly positive thinker, but it is in terms of problem solving, not in terms of morale or whatever. I have a course of action that I am going to follow, and I have decided on that course of action after deep consideration. I made that sound positive.

So, the positive aspects are just... I do try to handle things. I mean, I don't think... you know, I think that is a form of positive thinking, which is perfectly realistic. Just take the situation at hand, and deal with it and that is all anybody can do.

DO YOU FEEL LIKE YOUR GETTING MORE SUPPORT FROM WORK NOW? AND HOW DO YOU FEEL ABOUT THAT?

I liked it. I really felt... I am still not warm and fuzzy with most people. There is virtually no one there that I want to socialize with, and that wasn't true at my last job where at least a half a dozen of my coworkers I didn't hesitate to socialize with outside the office. But that is taking a risk, you know, because if you get too close to coworkers, then there is conflict and that complicates the situation. But really there is nobody here in that role yet, but I was at the other job for six and a half years, and I have only been

here for a year and a half and actually a third of that was out, so... But it is coming. I am waiting for the reaction... the reaction I am really looking forward to for one reason or another is when they find out that I am going in the Hall of Fame. It is going to be one of two reactions.

NOBODY THERE KNOWS?

No. There are only three people besides the executive director that knows. One is a person that works for me who I am reasonably close to. The two people that I rode up and back to Minneapolis with, one of them knew about it because she is the administrative assistant; the other one I told because she is one of my favorite people. But no one else knows, and I have no doubt that none of those people will say anything. I don't think anybody is going to talk. So, the executive director said she was going to announce it at the last meeting, so I just decided I would wait until it comes out officially, because I think it will be announced in St. Louis and we have eleven people going to St. Louis.

The reaction is either going to be pleasure from the happiness about it or the thought that I got it because I am buddies with the executive director, who is also in the Hall. Or complete and total disinterest. Those would be the three possible reactions. That sounds kinda silly that I have thought that all through.

THAT'S THE SELF-TALK YOU SPOKE ABOUT. GETTING BACK ON TRACK, CAN YOU TALK ABOUT HOW YOU FELT ON THE DAY OF DISCHARGE?

Shaky. I was definitely ready to be discharged. The week before I couldn't have said that because I was having vertigo still from the medicine and that scared the heck out of me, not knowing when that would hit and not feeling like I could ever let go of the wall or a chair, or the bed, or Cheryl. But it was a rainy, wet, and cold day. It was beautiful the day before and I got discharged on this horrible day. I was frustrated with the amount of time it was taking me because I had to get all my dozen or so meds from the pharmacy and they weren't known for their extreme speed. Cheryl had gone to do something, to check out... you were going to check out of your room and then she went out to lunch with a bunch of people, and one of the other family members had come in and said, "Is Cheryl around?" and I

said, "No, she is over... we're being discharged today. She said, "Oh well, a bunch of us are going over to Long John Silver's for lunch" and I said, "Well, I am sure she won't want to do that because we won't have time to do that." But of course, she went, while I sat in my room and stewed. I understood that cognitively, but emotionally I wanted out of there and I didn't want anything holding me up. I can't remember when I've been that tired before. Just the stress of having a doctor come in the morning and saying are you ready to go home and me saying yeah I am. That was stressful in itself. Because he was putting the decision in my hands. If he had felt otherwise, I don't think he would have even asked. So it was my decision to discharge, with his concurrence of course. It was just very emotional. There weren't very many nurses around that I know, so it wasn't real emotional. I was just absolutely exhausted, and then when I got home I had to deal with learning how to do this nighttime feeding thing, and have that clicking noise all night.

I got a better night's sleep that night than I had for the previous nine weeks. But I didn't get a really good night's sleep until I was done with the nighttime feedings. Then I really slept well and that is real important to me. So that day was up and down, you know with a two-hour drive without having much conditioning for a two-hour drive, as far as exhaustion. The nurse that came that night to show me how to do it thought I was going to be a real loser in terms of bone marrow stuff, because I was functioning at a very low level. She was just amazed the next night. She figured it would take me about ten days of her coming every night to do this and every morning to unhook me and do all the flushing. She quite dramatically revised her estimation the next time because I was back more to my normal functioning self and I asked intelligent questions and remembered stuff... She said it was like the ninth day.

DID YOU FEEL ANY ANXIETY BY NOT HAVING THE SURROUNDINGS OF THE HOSPITAL AND STAFF?

More so in the days preceding it. You know, when you are there for nine weeks in the womb, so to speak. And your every wish is catered to, it is scary. Knowing that there is somebody there that can help you in almost any situation. You know, I got home the first night and Cheryl informed me that she thought she was coming down with a cold. She had a sore throat. So I called the

hospital back to talk to Dr. Lee, and I said, "Can Cheryl sleep with me tonight? I have been looking forward to this for about nine weeks, not for anything sexual, but just for companionship. I have been in a single bed, and so has she." He asked if she had a fever and she didn't have a fever. But he said we had better give it a rest tonight and tomorrow see how things are doing. So, I think I pointed out to him if she had the symptoms then she wasn't contagious anymore. I had heard that about colds somewhere. But he didn't buy it.

THAT WAS DISHEARTENING.

Yes, it was discouraging. Just the capstone on the day. You know, I was out, but it meant a whole new life for me. There was no sense of euphoria, it was a change but that is about all I can say.

WHAT FEELINGS DO YOU HAVE REGARDING HOW THE BMT HAS CHANGED YOU LIFE?

I can still speak to that. I can't say that... I think having cancer has affected my life far more than the transplant did. The transplant was merely one more very elaborate course in my treatment. That is all it was and it was far more threatening and intrusive in my life. But it was still a treatment and I think that the fact that I like little kids more than I used to and I have tried to consciously play more, although I don't do very well. That is one of the things in a book that I read about cancer that talks about stress and then talks about pleasure and talks about dying and talks about some other things that are consistent. The transplant was just another form of treatment. So I don't know that... you know, it gives me a tiny bit of prestige. I can say... I can make reference to it and people go "Oh wow, he had a transplant". But I don't really trade on that much because I can only get so much mileage out of that. I guess I'm... for what it is worth or what influence I have, I guess I feel pretty good about the fact that I came through it. I have to believe that some of that was due to my own internal fortitude or mental discipline. So, I shouldn't question it.

ANY GOALS YOU ARE LOOKING FORWARD TO?

Well, I think that is why this last week with the lymph node has hit me harder than it would have before.

Because I had let myself start looking forward to... and now this is threatening it. Because I don't know what effect it is going to have. But I was looking forward making plans to having some reasonable certainty that I can count on going to Deluth camping over the Memorial Day Weekend. Even looking further ahead and going to the convention in the fall. You know, those are the things which I hadn't let myself do. That I didn't know what was going to happen. No one does, but I didn't even have a clue. So that is why I think I was so bummed, is that I was jerked back into the present. I had to shut down my future for awhile until this thing gets resolved. So...

HOW DO YOU DEAL WITH LIFE A LITTLE DIFFERENTLY AFTER THE TRANSPLANT?

Um, I am aware of the central theme of stress more than I use to be. Not the transplant, but again the illness. I think I am a little bit even more paranoid about illness since the transplant, even though my counts are coming up and everything. So I am not in a real problem situation, but I am trying to wash my hands more often, just as a precaution.

We have been over to our friends and watched their kids, and here we are entering a household with three young kids, talk about a breeding ground... it is like a miracle if we can get over there in between illnesses. Somebody is always sick and so, I think about that. We didn't go there once or twice because the kids were sick, early on after the transplant. We just avoided it. But I decided I couldn't live my life in a bubble, and I would have to take my chances. And I do. I thought about it when I flew, couped up in a plane, and I heard a story that there was a new strain of tuberculosis in Iowa...

IF WE ASKED YOU TO TALK TO ANOTHER PATIENT WHO WAS CONSIDERING BMT, WHAT WOULD YOU TELL THEM?

Um, I guess I would want to know what they wanted to know. I would probably follow their lead rather than burden them with information that they may not want. You know, if they are curious about the daily ritual, and that helps some people to know roughly what to expect. So I think I would tell them about Hickmans, because I didn't really understand exactly what that was and what was involved. I would tell them about the

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nursing care and the quality of nursing care, which I thought was pretty good. How the doctors arrange themselves so that they are on for a month and off for a month. Some of the things that they can expect in terms of appetite. But I guess the main point that I would make is that everyone's experience is different. There are no two patients that go through it the same. Even lots of good experience about how to control bleedings. I would just want to know what the patient wants to know. It may be helpful to gently prod them if they don't know what to ask because their knowledge base may not know where to start with questions. I would tell them to make sure that they get the manual, and that they read the book that is the compilation of the newsletters. To have somebody there and to plan on having a family member or friend or somebody there to do the little things for you that need done. Things like... well, I didn't realize that I could wear my own clothes and during the time when I was not having severe diarrhea, I wore my own clothes. But they had to be washed every day when I took a shower and Cheryl and her mom did a lot of laundry, and I hadn't expected that at all. In fact, one of our letters to friends, I said look at the bright side of this. I am not going to get hit by a car the entire time I am in the hospital. Cheryl won't have to do any of my laundry and that turned out not to be true! Because I was rereading that letter... So it helped to have people run errands, do laundry, and just be there to give the nurses a break, so you are not always asking the nurse. Cheryl would often go get stuff for me, and she felt needed to tell you the truth. So I think probably the routine and some of the things to watch for and ask about, to be assertive about medicine. Whether you need or not, to try and determine that yourself rather than what someone else says.

I mean most of time I went along with the nurse, but I always wanted to know what they were putting in me. There was once or twice that I called them on things... but they were doing something that didn't make any sense. For instance, they would bring me a can of pop. Cans of pop are not notoriously clean and here I am in a semi-sterile environment bringing in this can of pop that they are going to pour out of this can, over an unsterilized top of can. That didn't make any sense. You know, I said think about it. Knowing what to watch for when I was in the bubble wheelchair, the oxygen tube, I had to sit on the oxygen tube because they put

the bubble over the wheelchair and the oxygen tube... did I tell you this already? The oxygen tube comes in and it was... and I sat down on it without knowing it. They kind of rush you out of your room and bubble covers you up, and then the oxygen. I asked, "Where is the oxygen tube?" And one of the people from radiology, the transport people, picked it up at the end and gave it to me and I automatically put it up underneath my mask, because it really did the most good when I put it in the mask. Then I realized what I had just done. Here we had an unsterilized hand touching the oxygen mask, and then I was putting it up next to my nose and mouth and I use it and I was afraid I would croak. I just thought, I have just gotten all kinds of diseases and I am going to die. You know, I was really upset. It wasn't her fault. She... it would be nice if they knew better but there are so many transport people on too many different shifts to educate. So, I learned some things about that. That other is people are not as conscious of sterility. I would make sure that the patient knows it is their responsibility, ultimately, for their own sterility, or at least their own avoidance of it. They have the responsibility.

YOU FEEL THE PATIENT DOES?

Uh huh, very much so. It is ultimately their health. I mean that extended to a lot of things in the hospital, with the meds and with your care, and with decisions that have to be made. You theoretically should be active in these decisions, and often as not, you are not in that role. The patient needs to know they have a right to participate in their care.

WHAT THOUGHTS DO YOU HAVE ABOUT HAVING POTENTIAL BMT PATIENTS TALK TO A POST BMT PATIENT?

You know, I asked about it. Buroker said that he could put me in touch with a former transplant patient. But I never called to.. when I first, when I was in the hospital a fella came in and we talked because he had T-cell lymphoma. He is the only other person I have ever met that had T-cell and he came in and I kinda was like a brother to him. I didn't act that way, but I tried to let him know, and then I wrote him a letter later on the computer when I had the computer there. I think it helped him, I think it helped his morale. I would like to think so. I called Kevin today, and he is doing okay.

DO YOU WISH YOU HAD TALKED TO SOMEONE?

I don't know. I think I would have done better with written materials, official materials as opposed to someone's perceptions. Just because of the variations. I didn't have any information at all, and I for some reason acted out of character and wasn't very aggressive in going after it.

THAT SURPRISES ME!

Yeah, it surprised me too. I don't know why, whether I was just so uptight that I stopped functioning or felt so out of my element, or I was just that sick. You know, during the chemo time I wasn't feeling very good, as I recall anyway. You'll have to ask Cheryl.

So, I think I was more concerned with going out to Colorado and seeing my family and getting work wrapped up than I was... I maybe mentally blocked out going into this thing until the day I got there. Because I didn't want to worry about it. So I unconsciously, it certainly wasn't a conscious decision because I talked about it. But I talked about it very lightly and I didn't take it very seriously and that may have been a defense mechanism.

HAS LIFE BEEN WHAT YOU EXPECTED AFTER TRANSPLANT?

You know I feel like I have come pretty far pretty fast, not too fast, but fast enough. I am not surprised at that, but I think I expected to in longer... I am not really sure. I don't think I had any real perceptions of what it would be like, so...

You know, until this lymph node thing came along, I was to the part where I was far more worried about what my stomach is going to do as the scar tissue progressed, because of whatever it is going to do, my eating habits, and what impact that has on my life. I really thought that was going to be the next physical challenge for me. I really did.

WAS IT WORTH IT?

The transplant? If I've got lymphoma still, then I would say "Hell no", it didn't knock it out. If it did knock it out and this is just an infection and is no big deal, and the further away I get, the more aware I am of

being healthy again, being well again, then yeah I think it would be. If that is what it took, but there is always a doubt. Did I have to go through all that. But there isn't really any jump between chemo with CHOP-BLEO in the office and transplant. There is no middle ground. At least none that anyone told me about. I asked. So, I am going to be pretty disgusted I think if I went through all that and I still have lymphoma.

People could say "Yeah, but you had seven months of cancer-free life." Right, but for about half that time I wasn't functioning very well. Where does quality of life come in here. I don't think I looked at it enough. I didn't work a lot of weekends or a lot of nights and I never would bring work home with me. I think maybe twice in the last ten years I brought work home. If I can't work hard enough at work to get it done, and then the heck with it. I will go in early sometimes, not now, but I use to do that a lot. The more upset I got about things the harder I would work. but I think I am more conscious of quality, friends, socializing... Something we hadn't discussed.

To say that cancer patients who are a part of a support group live longer, some type of support group. They have done studies on that. I have never been big on support groups. But I do feel strongly for a social connection. So that is why I have been volunteering for this one local community group, and why I would like to find something else where I can actually volunteer a little bit more. I have the stamina to do it. I will probably, if everything is okay in the fall, I will be teaching photography again.

I BELIEVE, WE HAVE GONE OVER OUR LIMIT AGAIN. WE WILL CONTINUE EXPLORING YOUR FEELINGS AFTER THE BMT WHEN YOU RETURN FROM YOUR TRIP TO FLORIDA. WE WILL PLAN TO MEET IN TWO WEEKS, OKAY?

Sounds great.

APPENDIX F
INTERVIEW FIVE

APPENDIX F

Interview Five

THIS WILL BE OUR FINAL INTERVIEW. SINCE WE HAVE BEEN GOING OVER OUR ONE-HOUR TIME FRAME I BELIEVE WE WILL HAVE COMPLETED ALL THE QUESTIONS. I WILL MEET WITH YOUR WIFE TO ASSIST IN COMPLETING ANY GAPS.

IT HAS BEEN TWO WEEKS SINCE WE MET, YOU HAVE BEEN TO SEE YOUR MOTHER. LET'S TALK ABOUT YOUR THOUGHTS AND FEELINGS ABOUT YOUR TRIP.

One thing that was kind of a shock was we didn't get down to Florida until midnight because of delays on the flights, so we didn't get to the house until 1:00 and we were both pretty pooped because we had been up since 4:30 that morning. So it was even more of a shock to see my mother hairless, swollen face, eye patch, and unsteady gait at 1:00 in the morning. Even though cognitively I knew those things, it wasn't my mother standing there. It wasn't the mental image I had. It didn't bother me because of her illness, but just because it wasn't the appearance that I had expected. And the other interesting part about last week--my parents, while we were there, signed documents for a trust. So there was a lot of paperwork to be done and my dad was very much wrapped up in getting beneficiaries changed and the trust funded and a bunch of other stuff that I didn't really understand. It was a lot of pressure on him, most of it self-imposed, but nonetheless it was very real. I put out feelers to each of my parents individually, kind of testing the waters or just casually mentioning in conversation about the fact that I had a lymph node that was enlarged. Interestingly enough, both of them blew me off. They just shut right down and ignored the fact that I brought it up. As far as I can tell... I wasn't really hurt by it, I was just interested psychologically because it seemed to me that they had reached their saturation point and they simply couldn't handle anything else. They just could not handle it. Significantly, they were in a much better mood last night; they have signed up to go on a cruise; they were really upbeat. I called them and they asked about the scans and the lymph node. They had come back to a level where they could handle more than themselves. So I was just really interested to see

how they reacted to that. The only day that I really clashed with my father, who is very clashable at times, was the day after I finished the antibiotic. I didn't check for the lymph node until I did so, because I didn't want to keep poking in it. I checked for the lymph node and found still something. I couldn't tell if it was significantly different than the other side, or whether it was significant. The fact that I could find something really upset me, and so I was in a mood to be upset that day and my dad was a pill, his know-it-all worst I think. It really got under my skin and Cheryl's too. Overall, it was a good visit. My parent kept apologizing for breaking into tears which they did not do on a regular basis, but sporadically throughout the week. We kept saying, "It's okay. We have been there. It is perfectly fine. You don't need to apologize." We were concerned because my father kept writing my mother off in his language. I think the most shocking incident to us, and I suppose it is realistic and so maybe it shouldn't be shocking but it was. The attorney even said, "Well you are going to be filing a joint return this year, and you are probably going to be filing a single return next year." You know, the attorney I think... we like the attorney, he is a good guy and I am pleased with their choice. I wish we had him here because we haven't found a good one. But he was, I think, simply responding to my father's tone and atmosphere and approach. But it was still kind of eye opening. My feeling, I don't think they should ignore the situation, but neither should my dad talk like my mom is already dead, which he came close to several times. And I didn't know how to approach that. I felt like I should confront him on it, but I didn't know how. I feel real guilty about that, because I didn't do anything about it all week. I don't know how my own condition and with the prospect of any enlarged lymph node affected my approach to my parents. I really don't know. I don't know whether to think I did the best I could have for them or not. They said we really helped their morale and we made them laugh a lot, and we worked at that. So, it was I think a real good week. I am glad we went.

WHAT PROGNOSIS HAVE THEY GIVEN YOUR MOTHER?

That depends on who you ask. We injected a little bit of our philosophy into them. We were at the radiology oncologist, or whatever the technical name is, and he was a fairly abrupt person. His bedside manner was not

real warm and fuzzy. He said that they probably will need a head MRI and a chest x-ray at some point in the next month or so. Two things came out of that visit--one was, I told my parents, I really thought that they ought to go on their cruise before the MRI. I didn't say my reasoning, but my reasoning was that an MRI has three plus welcomes--neutral with no change and no significant information; bad news saying that the tumors have grown or at least stayed the same; and good news saying that the scar tissue is forming where the tumors were. Now to me, two out of three is not a good average because neutral or bad news is not good news. So I felt that they ought to go on the cruise not knowing what the outcome was, enjoy themselves, and base their activities on my mother's condition not on my mother's MRI report. And so they took this under advisement. Ironically the doctor, (the second doctor, not the one we went to when we were there, but their family doctor who is acting kind of as a general oncologist in this case) he said they ought to do that particular thing--go on a cruise first, because if they do have medical treatment for her lung, for instance, it would be better all at one shot after they get back and not interrupted. So they said that the doctor agreed with me, not for the same reasons. I was looking at mental and he was looking at medical but the outcome was the same. They are signed up to go on a cruise. The thing that was interesting about that visit was that their perception was that it was a bad news visit to the doctor. The doctor didn't say anything bad. He said that he observed that there was no change in my mom's condition. But when my father was... my brother called, and my father was talking to him and he said we got some bad news from the doctor. Cheryl and I kind of looked at each other and said, "What was that bad news?", because we didn't hear anything bad. We heard nothing good; we heard nothing bad; we heard nothing really in terms of significant news from the doctor, significant opinions or observations. He looked her over, she still had trouble walking, she had edema of the ankles from the steroids that she was on. Her eye, her vision, had not improved any. You know, everything was status quo. And so, he had really very little comment to me. It made me a little uncomfortable and this has been true all along. My parents noted to the doctor that I was the bone marrow son. Nothing like stereotyping. He looked at me and said, "Oh. You seem to be doing pretty well." Two weeks ago, I would have said I am doing very well. I am really going great guns. And then a week

and half ago changed it, or two weeks now. So I really am a little hesitant to say to people I am doing great. Because I really am not sure that I am. And I really... it is important to me to be true to myself and to be accurate. Which gets me in trouble some times, but my boss keeps saying I am doing great, and then I keep asking for it in writing and she won't do it. But it was one of those situations where I just kind of smiled when he said I was doing well and just nodded. I mean, overall I am doing well. In fact, the insurance agent that my boss was talking to because we are looking at switching companies because Principal's prices out of the market, or priced themselves out of the market so they don't want more business any more. Anyway, the insurance agent from some other provider noted my condition and that was a reason why that provider turned us down for insurance. He said he had T-cell lymphoma, and my boss said, "yes he does", and the guy said, "Oh, and he is still there?" and she said, "Yeah, working full-time." So I am not sure what perception T-cell lymphoma has or what impression the guy had, but...

SINCE BEING FACED WITH YOUR MOTHER'S CONDITION, WHAT FEELINGS DID THIS STIMULATE ABOUT HOW YOU FEEL ABOUT YOUR OWN DISEASE?

I don't think it really hit home in terms of upsetting me. To be honest with you, I was upset because it is going to put a lot of stress on my parents, and it is going to put the ultimate stress on my mother eventually. And I feel guilty... I was talking about this to Cheryl on the way home on the plane. I think somehow I have got some defenses built up somewhere that don't allow me to grieve in advance. Some people start grieving for someone in that situation long before they die. I have had very little of death in my family. My grandparents died but I wasn't close to my grandparents, so it didn't really... it was sad, I felt for my father but I really didn't get affected by it. I had been hit hardest in my lifetime by Cheryl's father dying. It really surprised me because I didn't know how strong my feelings were for him. But I can't find it in myself, in all honesty, to grieve for my mother yet. I am wondering if there is something wrong with me, quite frankly, in that I am not grieving for my mother and I am not really upset. I am upset, but not to the point of being bothered by it. I went down and we felt that we ought to act our normal selves. From the point we walked in the house and both were taken aback by my

mother's appearance, hopefully we covered ourselves well, I think we did--you know, all the way through, just taking things in stride and saying it's okay. It is all right to take our arm, and it is all right to avoid steps, and it is all right to accept a wheelchair. There is a point where she needs to do things, and my father I don't think is letting her do enough of those. But it didn't really hit home; I didn't really relate my illness to her illness and I am not sure why that is. We have taken different paths. She has never been in a hospital with any of this stuff. In her life, she has not recently. Yet I have spent fourteen or fifteen weeks in a hospital in two and a half years.

HOW DO YOU FEEL YOU ARE ACCEPTING THE FACT YOUR MOTHER IS DYING?

I don't know; that is what I am wrestling with. Cognitively I understand that. Cognitively I understand that there is going to come a day when my father is going to call and say mom is gone. I am going to have to deal with that; deal with my father which I have given as much thought to or more than my mother. I guess I am one that believes that death is no big deal; it is a lot harder on those left behind. Now when I get closer to it, I may change that, but at this point that is how I feel.

MAYBE PART OF THE REASONING HOW YOU ARE PERCEIVING YOUR MOTHER'S DEATH RELATES TO HOW YOU PERCEIVE YOUR OWN. MAYBE THE REASON YOU DON'T DWELL ON YOUR MOTHER'S IS BECAUSE YOU DON'T DWELL ON YOUR OWN.

That is very possible. I guess I have never really believed in the philosophy of one day at a time. My philosophy is more expressed as, "Plan things for the future because that is a magnet that draws you into the future, so make plans." And I have said that to friends and relatives.

I REALIZE YOU UNDERSTAND BEING SICK FROM THIS DISEASE, BUT WHEN YOU VISITED YOUR MOTHER I'M SURE THE PHYSICAL DETERIORATION WAS VERY VISIBLE. DID THIS PHYSICAL AWARENESS BRING ABOUT ANY THOUGHTS ABOUT YOUR OWN MORTALITY?

It really didn't. I got a double whammy because the day after I got back, the day I got back to work on Monday, there was a letter in my mail from the President of this

chapter of the National Society of Fund Raising Executives, NSFRE, which is one of my professional organizations, and it turned out that the immediate, that the person who technically was president this year, or last year I am not sure how long her term was, died last Thursday of cancer and I didn't know until I came back to work in January that she had cancer at all. She was diagnosed with bone cancer, and something else; it spread from somewhere else in September. In fact, Shreck was her doctor.

WELL, DO YOU FEEL LIKE SHARING ANYTHING ELSE ABOUT YOUR TRIP?

No, that's enough for now.

YOUR MOTHER'S DISEASE WAS VERY DIFFERENT FROM YOURS. LUNG CANCER DOES NOT HAVE A REAL GOOD PROGNOSIS AND DOES NOT HAVE REAL HOME RUN TREATMENTS, NO GREAT MAGIC. DOES THIS TRIGGER ANY ASPECTS OF YOUR DISEASE?

No. I could identify a little bit because it seems that though my illness has been responsive to chemo, it hasn't been completely responsive, if indeed I still have it. Because I would guess that the chemo that I got before the transplant, and the transplant, are just about as heavy duty things that they can throw at somebody and expect them to live through it.

Is that fair to say?

YES. WITHOUT THE NEW MARROW THERE IS NO WAY YOU WOULD HAVE LIVED THROUGH THE BMT.

Yes. Right, because it destroys the marrow.

WITH ROUTINE THERAPY YOUR COUNTS WILL GET DOWN TO 1000 OR MAYBE A LITTLE LESS, BUT WITH THE BMT THEY GET YOU DOWN TO ZERO.

Yeah, it was down to zero for days on end. I didn't mind the visit, I guess. I was more affected emotionally by my father and his obstinance at times. And my parents' lack of being flexible. You know, we came up with the idea of going out to the beach one day to the picnic tables by the beach, and picking up sandwiches at Subway, figuring that is the least painless way to go on a picnic and this would be no problem, you know, we would just buy everything at

Subway and it is no big deal. We went and it was a three-ring circus. Anything that could go wrong, did go wrong. It was still a major expedition to go on this stupid picnic.

It is just how my parents are. We didn't even have to do much. All they had to do was remember my Ensure. That was the only drink they had to bring. It worked out fine. Naturally, my father and I were out to the store for something else and the one sandwich they were out of was my father's and so Cheryl didn't dare make a substitution without checking ahead, and you know... Anyway, so it was just... we took... we didn't feel the first part of the week the obligation that we have in the past to get away. They really encouraged us; they are beginning to understand very slightly that quality time is better than quantity time and that it is okay not to spend 24 hours a day together when you see each other for a week. That is not real important, in our opinion for sure and maybe a little bit in theirs now. But on Wednesday we went out to Busch Gardens and spent the whole day there and got back about 7:00 p.m. that night. It was a nice break for us. I didn't feel real pressured but it was the next day that was kind of tense for us that I got disgusted.

I REALIZE YOU HAD TO WAIT THE WHOLE WEEK TO FIND OUT WHAT WAS GOING TO BE DONE WITH YOUR LUMP. WHAT WERE YOU FEELING ABOUT THAT AND THE SCANS?

I didn't wonder about the scans too much because if there had been a real significant change we would have been able to see it on the scan without a comparison. That was my opinion. So, I didn't really expect anything out of the scan. If it had gone in the other direction, if there was something on the scan in Iowa City and it shrunk that would be nice, but it still wasn't necessary for me to know. Nothing showed up on the scans, so I wasn't worried about it. I don't understand why the lymph node doesn't show up, but I know that resolution on a scan like that is not very high, it is not very precise in its description of what it is seeing. So the only thing I can figure is that the lymph node is so small that it just didn't show up.

ARE YOU STILL FEELING THE NODE?

I don't know. Buroker told me not to mess with it, and I wouldn't anyway. Because like he said, I could drive

myself crazy. So I will check it in a week, maybe two weeks when I come back to see him.

BUT PAIN HAS BEEN AN INDICATOR FOR YOU, NO PAIN?

Well, you see I have had the advantage of having gone through lymph nodes. When I first went through them in July of 1991, the sequence was a pain appeared, I thought it was a stiff neck and then one morning I was trying to feel what it was that was hurting so much and I felt the lymph node in my neck. That lymph node stayed there for a few days and hurt, and then it gradually decreased in size and stopped hurting and continued in place until I started chemo. I started chemo... that was in mid-July, and I didn't start chemo until the end of September. But, you know, two days, the next day practically after I started the CHOP-BLEO they went down. So I know that I have a history of having initial eruption of a lymph node with pain and then a decrease in the pain and a decrease in size. That is why I can't get my hopes up yet.

I CAN UNDERSTAND YOU DON'T HAVE A LOT OF FAITH.

I have very little faith right now. I have been told by too many doctors now that I am cured on too many occasions and I have developed a very cynical attitude about that. Talk to me in ten years, maybe I will believe it then.

BY THAT COMMENT, ARE WE TALKING ABOUT CURE?

Yeah. But, right now I regret the fact that I told as many people as I did that I was cured. But I really felt like that was a reasonable thing to say. I am one that believes that "don't mention it" is bad luck kind of stuff, so I rarely... it was almost out of character for me to tell people. In retrospect I wish I hadn't now because then I don't have to go back and tell them that it has come back. I wish I would have just let it ride and kept it to myself. So anyway, to get back to the lymph nodes. That is why I can't get too enthused about the fact that the pain has decreased and that the size has decreased, because my lymph nodes apparently are atypical, at least how the illness affects me is atypical and cannot be judged by the general population.

ARE YOU SAYING YOU ARE A LITTLE SKEPTICAL?

A lot skeptical. You know, I am glad that my boss thinks that I am doing great and that it is going to be okay, but as I told her today I don't know that. I won't say it if I don't believe it.

SINCE YOU HAVE THE RECURRENCE, HOW DO YOU FEEL ABOUT YOUR PHYSICIAN HERE BEING THE DRIVER OF YOUR CARE AGAIN SINCE RECENTLY IOWA CITY HAS BEEN IN THE DRIVER'S SEAT.

I don't know what communication there has been. I don't know if Gingrich even knows that I have had this recurrence, whatever it is. I didn't ask Buroker. I don't feel that this recurrence or relapse or whatever it is, is related to transplant. So therefore it is logical that Buroker be my primary care physician for it. I just don't think... it is eight months now and I don't think there is any connection. You know, the way it looks right now is that if this is a relapse or recurrence, the transplant bought me seven months at the very least. Seven months of lymph node-free life. I don't know whether that was worth \$270,000 and nine weeks in the hospital and discomfort, stress for my family and friends, I don't know. There is no way of ever relating that I guess.

I AM SURE THAT IS REAL HARD TO MEASURE RIGHT NOW.

It would be a lot easier to write the letter to Gingrich right now about asking him to defray his fee which...expect insurance, because I am not sure I got my money's worth.

ARE YOU THINKING ABOUT DOING THAT?

We had been considering that. Oh, that is one other interesting thing. The University of Iowa is the eventual end beneficiary of my parent's trust--the University of Iowa for cancer treatment and research.

THAT IS WONDERFUL.

Well, it is not an emotional decision on my parent's part. They shopped around. They found out what university or what charity would be willing to accept the conditions of the trust, which is that it will go... after my parents die it comes to my brother and I, after we die it will go to our wives, and after that it would go to any issue that we have, and only after everybody is dead does it go to the University of Iowa. So we are

looking at 50 or 60 years down the road, hopefully. But they were the most attentive, he wanted to give it to the bone marrow transplant and so Gingrich knows that this is coming. So I don't know how that would affect a letter that I send. It is not going to happen in Gingrich's office, I am fairly sure of that. But my dad was going to write a letter kind of saying the trust documents are such and so and he wanted to know the extent of our debt to the university. He was going to say he didn't want to pry into our affairs. The whole point of it was just to make a general reminder to the university that they may have as much as a half million dollars coming. It is going to be interesting to see what reaction we get if that happens. I don't mind him doing it, I don't care. He is not going to be blatant about it.

I FIND IT INTERESTING YOUR PARENTS CHOSE THE UNIVERSITY OF IOWA. WE NEVER THINK OF THE GRASS BEING GREEN IN OUR OWN BACK YARD.

You know, the odd part is that if he had asked me what research center or what cancer center I would prefer it to go to, I probably would have said Penn State Medical Center or to Penn State. The reason for that is, I look back as the best year of my life came my sophomore year in college, as the absolute best year overall. My self esteem improved at the greatest rate during that year. I had the most enjoyment and I felt the most fulfilled. So I feel very, very positive towards Penn State. It wasn't so much the school but that was the environment where it took place. So I almost wished that he had asked because I would have said, "Check into Penn State". But they went through the whole list in the library of places that accepted trusts, and Penn State was not on there, per say. But I feel like Penn State has affected my life for years and maybe in thirty years I will look back at the transplant and say it did the same thing for me. But it certainly wasn't near as much fun as college life was.

YOU HAVE HAD A FULL WEEK?

Yeah, it really was. And it started off with the twelve hour delay in our flight and ended with a couple hour delay here. But I think it was one of the better visits that we had. As my dad said, "Everybody was trying." I mentally said to myself that dad was more trying some times than others, but I didn't say it out loud. You

know, we went to a travel presentation, we went to Pizza Hut, you know...we do things and they don't and so it was a good deal that we went out. They needed a break. They needed to rest up after us.

FEEL LIKE YOU HAD SOME QUALITY TIME WITH YOUR MOTHER?

Umm Humm. I was afraid... the only nervous moment I had was that we rented a car and it was good that we did because that meant we could drive. That meant we didn't have to ride with my dad's driving. That's good.

I THINK WE COULD DO A WHOLE TAPE ON YOUR DAD.

I love my father, but I also acknowledge some of his less than strongfullness.

ARE SAYING YOU HAVE LEARNED TO RECOGNIZE HIS FAULTS?

Yes. He is human and we have also learned some compensation for them to keep our anxiety levels to reasonable points. So we rent a car and we drive. We also learned last Christmas that we don't like to be without wheels. It is very, very uncomfortable. We want to have that freedom of movement. Anyway, we had to return the car. There was that big storm the night before. So we didn't know if they were even flying and we couldn't get through to the airlines. We went over to the airport early to drop the car off, which we didn't need to do because it took all of twenty seconds and to get checked in which we did need to do because we didn't have seat assignments or we didn't have good seat assignments. So we were ready for an 8:30 flight by about 7:15 and were up to the gate. My parents insisted that they wanted to come to the airport to see us off. It would have been a whole lot easier for everybody if we said good-bye at the house and be gone. But they had to come! So at 7:55, they are going to start boarding at 8:05 probably and they still hadn't shown up and I am getting real nervous because I didn't even say good-bye to my mother. My dad went through the whole routine like he was never going to see us again in the house. My mother, though, was in the bedroom, and we said, "We will see you out at the airport", and she said, "Okay." And I didn't even say good-bye to her. So I was really upset because I was afraid that they were not going to make it. I got to the point where I called the house and there was no answer. So I figured, well they are on their way and we will just kind of play this one by the

ear. So they made it. They got to see us for all of ten minutes before we got on the plane. For that they drove an hour basically, a half hour up and half hour back.

My mom was kind of teary, my dad was okay. But I was glad that I at least got a chance to give my mom a hug and say good-bye, however permanent that is. We gave them each opportunities to talk about their feelings or to talk about heavy subjects individually and together. We didn't try to avoid them or go in our room and read. We would sit with them in the living room, with my mother in particular. Or I would make it a point to go out with my dad to run errands so that if they needed to talk we were there. They very rarely took advantage of that.

THEY MAY NOT BE AT THE SAME LEVEL AS YOU ARE, PLUS THEY MAY NEVER BE AT YOUR LEVEL?

Yeah. It is a good question. I really don't know. But we wanted to make sure that we are accessible. Who was it that was telling me about... Oh, they were telling us about a neighbor who would bring things over or come over to visit and they kept trying to bring up the fact that my mom was very ill. The woman would start talking about her corns on her toes or whatever. They were kind of miffed about the fact that she couldn't take an interest in my mother's illness, and I said, "It's a defense mechanism. The woman cannot handle it and that is the only way she knows how to cope is to pretend it is not there." You know, it was real clear, as soon as they described that, what was going on. They hadn't realized that. They just saw that as a lack of concern on the person's part. I don't think that is the case at all. The woman is not real close to my parents, but...

DID YOU FEEL LIKE THE COUNSELOR WITH YOUR PARENTS ON THIS SUBJECT?

Yeah. I think in my family on the big issues, I am the strong one now. My brother can handle procedural things. You know, I don't know why, but he made reservations for a cruise for my parents. I think without consulting them. Which I thought was a little odd. That is a lot of money to commit without anyone knowing about it. But it turned out that they couldn't go then for some reason. I forget why. They had to rebooked it, so it is okay. But I think that my brother

looks up to me and in a way my parents do too. My parents perceive me as having gone through a whole lot more than my mother has, even though our illnesses began almost at the same time. A few months apart. I can't put my finger on what I do differently except that... My parents tape record conversations with doctors and lawyers. They have read books. I think my mom told me this... She read a book on transplants, only it was like a doctor's book, a medical book, and not like this. So she made the decision not to say anything to us. But it was obvious from our comments that we didn't have a clue. You know, we didn't know what we were getting into. But she wished she hadn't read it now. Because it probably pretty clearly laid out the risks and the potentials.

THOSE BOOKS HAVE NO FLUFF.

No fluff. It didn't sound like it anyway. I don't know what book it was. I guess I just focused on... I get a lot of my information from the doctor, and I ask as many hard questions as I can. But I don't want to read something... the doctor can adapt his answers to my case. A book cannot. A book can only give statistics, can only give maybe the worst case scenarios and that is not very good in my opinion.

THE BOOKS GIVE YOU AVERAGES.

And I am not average. There may never be a textbook person, but that is why I don't read them. My parents insisted at one point on sending me something about T-cell lymphoma and I think it said there that the survival rate of T-cell was 40-70%. But that didn't matter to me; I didn't want to hear it. I didn't want to read it. But it still didn't really bother me a whole lot.

So I think to answer the original question of source knowledge, I know how to deal with doctors and nurses. I know better. It works better for me when I have a relationship with them. I know how I react to a lot of things. I didn't have any real insightful questions to ask the doctor when we went to see him. I would have liked to. It would have been nice to come across brilliantly, but I didn't. I don't know if there is such a thing, but I feel like I have been a reasonably successful patient. Doing everything I can.

YOU HAVE TAKEN RESPONSIBILITY OF YOUR HEALTH, TO LEARN AND USE THAT KNOWLEDGE TO HANDLE YOUR HEALTH.

I have always remembered something I heard in an academic session at a conference where they were reading research papers. There was this one guy who had a paper about decentralizing your sense of control. What it means is that you give up responsibility for your own actions. You put the reasons behind your actions on somebody else.

I don't remember what he was researching. But I remember that term and if I want to impress them I just say, well you just decentralized your sense of control. They are going, "What?"

You know, that is really what it comes down to. You absolve yourself of all blame for it. I have always thought... you know, I am in control as much as possible. It comes back to cancer being an illness that renders a lack of control or feeling of lack of control in the patient. You know, a hospitalization just really magnifies that because you are so dependent on everybody else.

HOW WOULD YOUR WIFE DESCRIBE THE PERSON YOU ARE NOW?

I don't know. I feel like she still looks to me to take the lead in our relationship. It is not something that I necessarily want. I look at ours as a partnership as opposed to... I don't want to be a father figure. The last thing I want to be for my wife is a father figure, and yet that is how a lot of relationships evolve. But I think that even through my illness, she is dependent on me to take a certain amount of.. or for a certain amount of strength. Certainly she has provided a lot of strength to me because she very matter-of-factly approaches the situation. I don't think excessively, but she doesn't get all jammed up about it. She said to several people in these last couple weeks that she is... They asked how she was holding up, I think was the usual question, in light of the recent developments. She said that she wasn't going to worry until she had to. I think that is nice to say that. I am not sure that she buys into it completely, at least I would hope not. I think she still sees me as the person that I was. A lot of my underlying values and integrity and abilities haven't changed a whole lot. I think some of my superficial interests have. I don't do as much

photography as I used to and I don't tolerate inconveniences. I want to streamline some of my life I think. But they are relatively superficial things. Like not hauling around three lenses, a camera body, and a flash any more. I would rather get a pocket point and shoot which I am still a little embarrassed to use.

I saw myself as a professional photographer at one point or another and it is just real hard to use the same camera as the general population. Our relationship is close but I don't know as it is measurably closer than it was. I'd say a bigger moment in our lives, our mutual lives, came after about three years of marriage when she went out to Colorado for a three-month internship and we were apart for that entire three months. In fact, didn't have really easy access to phones. That really focused ourselves more because we didn't take each other for granted after that and I don't think we have since that time. We have come through some ups and downs.

WHAT WOULD SHE SAY IS DIFFERENT ABOUT YOURSELF IN COMPARISON BEFORE YOU WERE DIAGNOSED?

I would like to think that I am more tolerant, particularly of friends. I really try not to be critical on my friends. They are what they are and who they are and I am not going to change that. I don't think I want to now. They have to live with themselves. That is not my problem. So in almost every case, I had friend after friend apologize for not writing, not calling, not doing anything when I was ill and when they knew I could use some help and I said, "It's okay. You did what you had to do and what you wanted to do, and what felt comfortable to you."

ARE YOU SAYING PRIOR TO THAT, YOU WERE MORE CRITICAL OF YOUR FRIENDS?

Oh yeah. I have been critical all my life, I think, and I have mellowed as we have gotten older and wiser and a little less obnoxious. I even got... the peak for me, I have come downhill since thank goodness... but when I was in college, I was really stuck up for awhile because I knew that in my department I was one of the top students. I had never been that in any school before so this was a novelty. There was one class where I was the only student in a class of fifteen or twenty, for a higher level class so it was reasonably demanding,

I was the only one that had my project in on time. I really... I think I went on at obnoxious lengths about that. I feel and feel to this day that it is important that things at school be turned in on time. I have gotten mad at professors that just blow it off because I don't think that is preparing students for the real world. That is part of the issue there in college. But I really... finally somebody had to say, "Gordon, you are really just puffed up like a balloon and had better settle down." So I am glad that the professor told me that. It was a good lesson. I still have trouble with it. I wouldn't make a real good active Christian. I am too full of pride at times and it is probably a false pride. It is more out of a sense of insecurity rather than a real deep-rooted thing. But I would say I am more tolerant. I don't feel as guilty if I spend a day reading on a weekend instead of vacuuming the floor or working outside.

LEARNING TO LOAF?

Yeah. In fact, recently I have been actually staying up late and sleeping in later. I have never done that in my life. But I was up until 11:30 last night which is the wee hours of the morning for me. I think I have just mellowed out and I am not sure why. I am not sure if it is a result of the experience or a result of maturation.

I know that my self-esteem is better because one thing, unfortunately, it took this illness to do, it told me how my friends and coworkers, particularly friends and colleagues not coworkers, felt about me. That has been an enormous boost. I think I said that before, but it's still as true.

WE TALKED EARLIER ABOUT SUPPORT GROUPS. CAN YOU ELABORATE MORE ABOUT THIS AND HOW DO YOU FEEL ABOUT THE SPIRITUAL COMPONENT IN YOUR LIFE?

Well, somebody asked me last night why I has started coming to this group called the Adel Concerned Citizens Committee which I feel is kind of a name for a group that is doing some good things. Maybe we could have come up with something with an acronym or something, but anyway I said, "Well, there were several reasons and I said number one is I wanted to get involved and to get to know some people and this seemed like a good way to get across to different people because there is young

and old, more old than young, but still there are some people my own age. I said also that they have done studies that seem to prove that people who are members of groups who are connected to other people some way, be it by marriage or friendship or group membership, cancer patients particularly live longer than those who don't." I said, "I have tried support groups and I find them very depressing, so this is my substitute for support group." I feel pretty much the same about religion. Any one of these can work for spirituality. I am involved. I am appreciated. I have been to all three meetings and already I have had more than one person come up and say what an asset to the group I was, partly because I am a fresh breath of air, I guess. I don't like to put up with that meetings that go on for three hours. We went an hour and a half last night and we were still on the first item on the agenda. Give me a break folks! I could identify why and I understood that part of it was socializing and that was a necessary part of that group. That is one reason I went. So it was okay. But, there were some other things which were not necessary and terribly frustrating to someone who has been running groups since I was sixteen. After twenty years, I know how to run a good meeting, and it is real hard for me to suffer with fools babbling. So I guess, in terms of the community support, there needs to be some opportunities for connection. I think it needs to be more than a support group just because the nature of support groups in my mind are to focus off and on the illness for the individuals. Now that helps some people and I am glad for them, but if I am consistent to my, or true to my philosophy, "I am going to live my life as best I can and cancer is simply one aspect of it; it is not the focal point of my life; it is not the central point of my life but is merely a part of it. More significant sometimes than others. But if that is the case, then I don't want to go to a group where I focus on my illness. I want to go to a group where I focus on life and living and let the illness do what it may. So...

DO YOU FEEL PART OF THE REASON A SUPPORT GROUP DOESN'T WORK FOR YOU MIGHT BE THE MIX AND MULTIPLE LEVELS PEOPLE ARE AT?

Yeah, and different mentalities, and different approaches to their illness. I remember going to a support group back in Maine for a few months, and I remember commenting that I was crying more than I had

previously, which is not unheard of with cancer patients. I still remember one woman remarking, she said, "I have been crying for ten years." I thought, how sad. That is really too bad. She was fighting breast cancer and it was kind of a delaying action I suppose. Although ten years' survival with whatever cancer she had, ten years of any cancer, you are doing all right.

And it wasn't licked I don't think. She was still fighting it. But I still thought... I can see the initial grieving process with tears, but after that... no, I don't think so. Not for me anyway. I still cry, but it takes outside stimuli to do that. There was a Peter, Paul & Mary concert on IPTV this week and I saw it first down at my parents because they are also doing their fund raiser now and we like IPTV. It was Mary of the group saying a poem that she had written for her daughter while she was holding her granddaughter. In other words, she said a poem that she had written years ago, holding her little granddaughter which was like the spitting image... blonde hair and the whole nine yards. Then they would cut away to her daughter periodically and it made me cry.

DO YOU FEEL LIKE YOU APPRECIATE THESE THINGS MORE?

Maybe, I don't know. I just react more strongly to them now. It was really hard watching the show with my parents because I didn't feel as comfortable there, ironically I just didn't. But one person that I am willing to cry in front of regularly is Cheryl. She still tries to comfort me everytime I do. I don't necessarily want comforting; I just want the opportunity to cry.

WITH ALL THE CHANGES IN THE PAST FEW WEEKS, HOW FAR IN THE FUTURE ARE YOU PLANNING AND WHAT ARE YOU PLANNING?

I have had people tell me and I have read it in books occasionally, one indication according to various individuals, of a survivor, particularly a cancer survivor, is the answer to the question, "How long do you want to live?" Supposedly cancer survivors say, "I want to live to be 100." Well, here again, my realism kicks in. My family on my father's side have gotten into their late 80s. My mother's side died in their 60s. I figure, the number I pick is usually around 70. I don't want to die an invalid, cripple, mindless,

burden on somebody else. I have often thought if I could just tell the precise moment when I was about to lose my ability to function normally, then I would go up north someplace and walk into a snowbank and just go to sleep. Unfortunately, I don't think there is a little buzzer that goes off in my head.

You are right about this last couple of weeks changing my perspective of the future. Right now I am not looking beyond the end of this year. I am not saying that I am not going to make it to the end of this year, but I am now scared to plan. Because, I am a little gun shy. You know, I worked for three years to help on the convention in 1990 that I was a part of and I couldn't go to. So I am going to be real anxious until I get to Minneapolis and I really understand that I am going to make it to this convention. It is very important to me. You know, I had thoughts for awhile, maybe I said this last time I don't remember. Well, I am elected to the Hall of Fame and they can't take that away from me. I may not be there to accept it but by gosh I am going to be in the Hall of Fame. You know, I want to be there, but I really... the thought of planning a cruise next summer or something like that or a year from this summer, I can't do it. I just can't look beyond, and part of it is until today our income was uncertain and our scheduling was uncertain. Part of it is what my parent's situation is going to do to us. I figure that is... just because of logistics that is going to be short term duration. We can't go down there every weekend. We can't go for an extended period of months or even long number of weeks. If I was going to predict, I would say that we will hopefully visit with my mother at Christmas. It is their turn to be visited at Christmas. We switch back and forth. So I expect at this point to have one more visit with my mom and dad, and then I will have to go down and help with funeral arrangements and whatever and to be there for my father. But I am not focused beyond this year. I can get to October and probably to Christmas, but I can't focus very far beyond that and I feel a little guilty about that I guess.

YOU FEEL LIKE YOU WERE PLANNING MORE BEFORE THE RECURRENCE?

I was starting to. One of my indicators of the disease is that before I became ill I was very much driven towards the role of executive director in girl scouting.

Part of that was because I was ambitious and part of it was I wanted to escape my situation back in Maine. Since becoming ill, that has completely been wiped from my mind except for an occasional thought. Every once in awhile I will think, "Boy, it would be kind of neat to do that." But then I think about all the crap that goes with it and I say I don't want that in my life. So I think that once I start focusing on a career advancement again and advancement in my profession organization. You know I have had dreams and day dreams occasionally of being president of AGSES. That would be as much or more of an honor than the Hall of Fame. And so, at one point, I thought twenty years in the future was a possibility. It would take that long, but was a possibility. I don't think about that any more. I guess because one of defense mechanisms is that I don't like to be disappointed. So I would rather think the worst and be pleasantly surprised than to think the best and be disappointed.

WHAT ONE OR TWO THINGS IN THE ENTIRE PROCESS WOULD YOU SAY HAS HELPED YOU THE MOST IN GETTING THROUGH UP TO THIS POINT?

I think probably friends even more so than family. You know, I think the love of my parents, brother, and my uncle, recently, have always been there. I get a kick out of the fact that my dad now has this little catch phrase in which every phone conversation we have now he says, "Our love to you both." I can just sit there and predict when it is going to come. It is almost like a good luck charm kind of thing. He has to say it every time to prove that. So I think that helped me get through it. I think having a source of knowledge... you know, Buroker hit it right on the head. If I know what the situation is, I can handle it a whole lot better than when I have no knowledge or no information. I felt ten times better after I was into see him the week before last than the night before. So I think having a reliable source of information and for help was a big part of that too. Knowing that I could call. You know, and I try to use that wisely. That night I called to see who was on duty. If it would have been Buroker, I would have said have him call me. But it was Morton or Westberg or somebody, and it was nothing they could do for me. As Buroker said, it was not a medical emergency and what I thought a few minutes afterwards was, "No, you're right." I know that it was not a medical emergency. It was a mental emergency. But having

Buroker, you, Pat and Michelle and Gingrich, and all these people to turn to means a lot to me--knowing that we have a good relationship that I think is based on trust and mutual respect. So I think those are probably some of the things.

IF YOU ARE UNCOMFORTABLE ANSWERING THIS NEXT QUESTION JUST SAY SO, OKAY? IF SOMETHING TURNS OUT PRETTY SERIOUSLY ABOUT YOUR RECURRENCE AND YOU HAVE TO FACE MORE THERAPY, WHAT THINGS WOULD YOU FEEL?

It is not an uncomfortable question, but I really try hard to put my life up to date; more so in the last few years probably. But I try to leave myself on good terms with my friends and I try to write more often, and I try not to leave untied ends, loose ends is what I mean to say.

That's it. Pretty simple.

WE HAVE BASICALLY COVERED ALL THE QUESTIONS I HAVE FOR THE INTERVIEWS. MY LAST ONE IS TO ASK YOU WHAT ELSE DO YOU WANT TO TELL ME?

The only thing that occurred to me... I don't have any other questions that I want you to ask me. But you asked me last week that if... was it an issue with me if I had to have chemotherapy. I think you were gently hinting that I really have two choices of therapy if this is a lymphoma, one is radiation and one is chemotherapy; if the lymphoma comes back to my abdomen where I cannot have any more radiation, then that leaves me with one option and that is chemotherapy. That means that I will probably lose my hair and that has become fairly important to me. It has been important all along. But I guess I have come to associate my periods of good health with hair and my periods of weakness and ill health with the lack of hair. I decided that yesterday, that I have come to associate those two things.

WHETHER IT IS RIGHT OR WRONG?

Yeah, it is not logical. It is an emotional thing. But it certainly is something that I don't want to have happen again. One of the things I want most is to go to Minneapolis to the convention in the fall, looking as I do now, or at least as good. I do not want to go there without hair. If I had to I would, but it is just real important to me and I am going to stall against chemo

until afterwards.

That's till October and I feel like I have a reasonable argument, I think, in that chemo has not cured me. We might as well give radiation another shot at it.

IF IT IS NOT NEEDED TO THE ABDOMEN.

So I have got to keep it out on the extremities, either in the groin or up on the shoulder or neck, or whatever. My dentist told me if I got radiation, that I would see him first and they would do x-rays to make sure I don't have any cavities. Because I gather that any radiation up around my jaw would exacerbate the cavities. So I guess, that is really my greatest concern. I am relieved to know that there are some things that can be done. I guess I'm cognizant of the fact that there is probably no cure-alls in existence right now. But I was thinking this morning, "Well, even if I still have lymphoma and even if there is no final solution to it in terms of a cure, maybe I could hold on for enough years that something will come along."

That is the next best case scenario to being cured.

POSITIVE THINKING, GOOD.

The other remark I wanted to make involved a subject I talked about only briefly and I don't have a whole lot to say about it even now. It involves the feelings of being close with someone. I have to admit I was so sick and I am still concentrating so much on getting healthy and just feeling better that having relationships is not something I think about or even worry about very much. You might say I am just now starting to look at a woman as a woman. Cheryl has not made this a big deal either. Yet, the desire to want to be close or together has grown even stronger than before and that is what I focus on.

I WOULD SAY THAT IS YOUR DEFINITION OF INTIMACY.

DO YOU FIND YOURSELF THINKING ABOUT YOUR DISEASE MORE NOW?

Umm Hmm. Everytime I get a little twinge in my arm, I think about it. For some reason right now, and I am not sure why, some of the radiation damage in my abdomen, not so much my stomach but my ribs and lower abdomen, is flaring up. It does this periodically so that there are

twinges of pain when I move. As far as I know, it is not necessarily radiation, it could be chemo too. It could be what they gave last summer. It is having a residual effect of some kind because I can't fathom any physiological connection between lymphoma recurring and pain in the muscles, the musculature, of my abdomen. Those two are not connected as far as I know and so I have to conclude that it is probably to do with the chemo and just a kind of settling of my system. So that is occurring, but I just... I take a couple Tylenol in the morning and a couple in the evening or late afternoon, and that helps me a lot. I am still having trouble sleeping. I slept fine the night before, or almost. I woke up at 3:00 and couldn't go back to sleep.

TALKING IN YOUR HEAD?

No, I have shut it right down. I have had problems this last week with my "problem child".

SO YOU HAVE BEEN HAVING SOME OTHER STRESS RECENTLY?

Well, one interesting thing happened this week. I had a long conversation with the consultant who is helping up with our capital campaign. I have been reluctant... I believe in employee loyalty and loyalty to employees, but I have a situation where I felt that the consultant needed to know what I was dealing with and the fact that I simply, especially with the recent physical situation, I am simply not going to confront it or deal with it is a real direct way. It is just not important enough to upset me or to be upset because of it. So I told him, "Theoretically, I should put my foot down and take care of this, and really play hardball. But, (A) that is not my style, and (B) it is not just something I want to do right now. It is just not important to me." I have a hard time with myself sometimes because I know what I should be doing as a supervisor and I am not doing it. So I am not doing the best job that could be done and that is hard.

DO YOU FEEL LIKE YOU ARE LETTING YOURSELF DOWN?

Yeah, that's right. That is exactly right. But it is the lesser of the two evils at this point. I forget what got us on to that, but... I made the decision to inform this consultant and she really was nice about it. She said, "You got to do what you got to do, and

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sometimes that is the way it works out." I know what I should be doing, but I just can't bring myself to do it. So, I am admitting weakness on my part and it is hard.

I know what I should be doing. It's not going to get done, not in the near future anyway.

MAYBE YOU ARE JUST PRIORITY PLACING. THERE ARE A GREAT DEAL OF MANAGERS WHO FUNCTION THIS SAME WAY BUT THAT DOESN'T MAKE IT ANY EASIER FOR YOU.

Yeah, because I have real high standards. I am not saying that everybody doesn't, but... I think I have said before that I have failed at very few things in my lifetime. It is real hard to fail at something, or to knowingly fail. It is just real hard. I got, really, too used to being successful at things. Maybe not on the first try, but eventually.

YOU WILL WHEN YOU ARE READY.

Yeah, it is going to work out eventually. But I look at the real positive relationship I have with the other person now much better than the person who I had to leave because of illness. It is joy to work with her. We laugh a lot. We talk. We work together. She is open with me, as far as I know. There is still a barrier because she... A lot of the people who I know that are Black have a barrier around themselves, they have space. And I understand why. So, I know that she is not really opening up to me.

MAYBE SHE IS AS MUCH AS SHE CAN.

You know, we have a ways to go before complete trust is built and it may never be built. Just because we are too different. So, that is a balancing factor that I didn't have before. I feel like she and I are developing into a real good team. Things are working out well there.

ANYTHING ELSE?

No, I feel like I've shared all I can. I have looked forward to these and have enjoyed doing this. Are you going to talk to Cheryl?

YES, WE WILL PLAN AT MEETING NEXT WEEK IF THAT'S OKAY WITH YOU GUYS.

Since we have met here for all the interviews here and you just moved into your new house, let's meet at your place, if that's okay with you.

THAT SOUNDS GREAT, I'LL HAVE DINNER AND THEN I WILL LET CHERYL SHARE SOME OF HER THOUGHTS AND FEELINGS.

THANK YOU BOTH FOR HELPING ME WITH THIS STUDY.